

University of Warwick institutional repository: <http://go.warwick.ac.uk/wrap>

A Thesis Submitted for the Degree of PhD at the University of Warwick

<http://go.warwick.ac.uk/wrap/77126>

This thesis is made available online and is protected by original copyright.

Please scroll down to view the document itself.

Please refer to the repository record for this item for information to help you to cite it. Our policy information is available from the repository home page.

**Coping with Death and Bereavement: An Exploration
of Older Adults Bereavement Outcomes and
Community Nurses' Perspectives**

Annabel Goodall

Thesis submitted in partial fulfilment of the
requirements for the Degree of Doctor of Clinical
Psychology

University of Warwick, Department of Psychology
&
Coventry University, Faculty of Health and Life Sciences

May 2015

Contents

Contents	ii
List of tables and figures	vi
List of abbreviations	vii
List of appendices	ix
Acknowledgements	x
Declaration	xi
Summary	xii
 Chapter One: Contributory and protective factors in bereavement-related-	
depression for older adults experiencing spousal loss	1
1. Abstract	2
1.1 Introduction	3
1.1.1 Spousal bereavement in older adults	3
1.1.2 Depression as a bereavement outcome	4
1.1.3 Bereavement-related depression in older adults	5
1.1.4 Rationale	6
1.1.5 Aims	7
1.2 Method	7
1.2.1 Operational definitions	7
1.2.2 Inclusion/Exclusion criteria	9
1.2.3 Search strategy	9

1.2.4	Quality Assessment	11
1.3	Results	11
1.3.1	Pre-loss depression as a predictor of post-loss depression	24
1.3.2	Personality factors	25
1.3.3	Contextual factors	26
1.3.4	Personal resources and coping	31
1.3.5	Quality and nature of the marital relationship	36
1.3.6	Demographic factor	38
1.3.7	Additional critique	39
1.4	Discussion	41
1.4.1	Protective factors	41
1.4.2	Contributory factors	42
1.4.3	Undefinable factors	44
1.4.4	Limitations of current review	45
1.4.5	Future research	46
1.4.6	Clinical implications	46
1.5	Conclusions	47
1.6	References	48

Chapter Two: ‘Traversing the Unpredictable Terrain of COPD’: A Grounded

Theory study of community nurses’ experiences of working with people who have COPD

2.	Abstract	58
2.1	Introduction	58

2.1.1	COPD and COPD nursing	59
2.1.2	Nursing: an emotionally demanding occupation	61
2.1.3	Palliative and End of Life care	63
2.1.4	Community nursing and palliative care	64
2.1.5	Research aims	65
2.2	Method	66
2.2.1	Design	66
2.2.2	Participants	66
2.2.3	Measures	67
2.2.4	Procedure	68
2.2.5	Recruitment	68
2.2.6	Interview	68
2.2.7	Ethical considerations	68
2.2.8	Analysis of data	69
2.2.9	Issues of quality	70
2.3	Results	71
2.3.1	Conceptual category 1: Working with Time	76
2.3.2	Conceptual category 2: Death: Travelling to The Precipice	77
2.3.3	Conceptual category 3: Managing the Reality of COPD	79
2.3.4	Conceptual category 4: Trusting Relationships	80
2.3.5	Conceptual category 5: Giving	83
2.3.6	Conceptual category 6: Evaluating Own Resilience	84
2.3.7	Conceptual category 7: Negotiating the Limits	87
2.4	Discussion	89

2.4.1	Summary of findings	89
2.4.2	Strengths and limitations	94
2.4.3	Clinical implications	96
2.4.4	Future research	98
2.4.5	Conclusion	98
2.5	References	100

**Chapter Three: Reflections on speaking with community nurses who work
with people who have COPD** 107

3.1	Introduction	108
3.2	Resonating experiences: working with death and dying	108
3.2.1	Resonating experiences: the reality of COPD	114
3.3	Grappling with Grounded Theory	115
3.4	Conclusion	117
3.5	References	118

List of Tables and Figures

Chapter One: Literature Review:

Figure 1. Search strategy	10
Table 1. Inclusion/Exclusion criteria	9
Table 2. Summary table of papers (Selected papers for review)	13

Chapter Two: Empirical Paper:

Figure 1: Grounded Theory model representing how community nurses experience and manage working with people who have COPD	73
Figure 2a & 2b: Conceptual categories and associated axial codes	74

List of Abbreviations

β	Beta - Standardised coefficient (slope) in multiple regression
B	Unstandardised coefficient (slope) in multiple regression
BME	Black and Ethnic Minorities
BRD	Bereavement-related depression
COPD	Chronic Obstructive Pulmonary Disease
CLOC	Changing Lives of Older Couples study
CQC	Care Quality Commission
DSM V	Diagnostic and statistical manual of mental disorders: DSM 5
EoL	End of Life
F	F statistic showing if a group of variables are jointly significant
GOLD	Global Initiative of Chronic Obstructive Lung Disease
GT	Grounded Theory
IPA	Interpretive Phenomenological Analysis
LCGA	Latent class growth analysis
M	Mean value
NHS	National Health Service
OLS	Ordinary least squared regression
ONS	Office of National Statistics

p	Value showing the estimated probability of rejecting the null hypothesis
R&D	Research and Development
SD	Standard Deviation
SE	Standard Error
SES	Social Economic Status
t	T statistic showing if a single variable is statistically significant
WHO	World Health Organisation

List of Appendices

Appendix A: Author guidelines for Journal of Aging and Mental Health and Qualitative Health Research	119
Appendix B: Quality checklist	124
Appendix C: Descriptions of longitudinal studies	125
Appendix D: Interview Schedule	128
Appendix E: Participant Information Sheet	130
Appendix F: Demographics Questionnaire	134
Appendix G: Ethical Approval Letters	135
Appendix H: Consent to Participate Form	141
Appendix I: Post-interview Information Sheet	143
Appendix J: Excerpt of Coded Transcript	144
Appendix K: Example of Memo	146
Appendix L: Table of Categories and Codes	147

Acknowledgements

Thank you to all of the nurses, not only for giving up your time to be interviewed for this project but also for helping me to learn so much about the work you do; it has been a privilege to do this with you.

Thank you so much to my research team – Carolyn, Magda, Jane and Laura, who have supported me throughout the duration of this project and without whom I am certain it would not exist. Thank you to Carolyn for all for your many words of advice, not least for teaching me how to prune. Thank you to Laura, for holding onto my research baby while I looked after my own; for your enthusiasm and passion, for helping me to flick away “the gremlin” and for helping me to believe.

Thank you to my family and friends for your ongoing support and encouragement throughout this process. To my parents for all that you’ve done in motivating me to achieve this goal – I’m very lucky to have you all. To Norman and Judy, for all that you do to support me – it wouldn’t have been possible without you. To all of my friends, particularly Bernadette and Claire, for your daily words of support and encouragement. To my fellow trainees from the 2011 and 2012 cohorts, especially Jen, Tanagh, Amber and Jo B for being on the journey together.

And thank you, Simon, my wonderful husband, without whom I am not sure where I would be. There are no words to describe how grateful I am for everything you have done in supporting me. And lastly but by no means least, thank you to my darling daughter Hetty, for stopping me from becoming consumed, for helping me to see life and for giving me the most gorgeous cuddles I could ever hope for.

Declaration

This thesis has not been submitted for an award at any other university other than the Universities of Coventry and Warwick, and is the candidate's own work.

This thesis was prepared with the assistance of Dr Carolyn Gordan, Dr Magdalena Marczak (Academic Supervisors) and Dr Laura Hayward (Clinical Supervisor) who commented on drafts prior to submission.

Chapter One: The Literature Review 'Contributory and protective factors in bereavement-related-depression for older adults experiencing spousal loss' was prepared for submission to the Journal of Aging and Mental Health (see Appendix A for guidelines)

Chapter Two: The Empirical Paper "Traversing the Unpredictable Terrain of COPD': A Grounded Theory study of community nurses' experiences of working with people who have COPD' was prepared for submission to the journal of Qualitative Health Research (see Appendix A for guidelines)

Summary

The inevitability of death as a part of existence means that it will affect everyone at some point during life. This thesis examines issues relating to death from the perspective of those who have been bereaved of a spouse in older age. It also explores the experiences of community nurses working with patients who have Chronic Obstructive Pulmonary Disease (COPD) – a palliative condition.

Chapter One: The literature review aims to critically evaluate factors considered protective and/or contributory in depression in spousally bereaved older adults. Several factors were identified from the literature with high variability between findings, which prevent clear conclusions from being made. This variability was discussed in terms of conceptual and methodological limitations. The implications of this study suggest the importance of retaining the individual experience of loss at the centre of bereavement intervention for this clinical population.

Chapter Two: The empirical paper aimed to explore how community nurses experience and manage working with people who have Chronic Obstructive Pulmonary Disease (COPD). A Grounded Theory approach generated a model representing how participants coped in their roles. The core category 'Traversing the Unpredictable Terrain of COPD' showed how working with the reality of COPD required nurses to engage in the constant process of pulling towards and pushing away from death. Clinical implications indicate that all nurses be offered appropriate time for reflection and the opportunity to develop advanced communication skills.

Chapter three: This paper summarises a number of reflections made by the author throughout this research journey. These included prominent personal experiences that resonated with some of the emerging concepts and categories. Further reflections were made about the process of conducting qualitative research, specifically in relation to utilising Grounded Theory.

Chapter One

Literature Review

Contributory and protective factors in bereavement-related-depression for older adults experiencing spousal loss

Word Count: 8016 (excluding tables, figures and references)

Abstract: 244

Target Journal: The Journal of Aging and Mental Health

1. Abstract

Objectives

Spousal bereavement is associated with depression in older adults. Research has shown that the symptomatology of 'bereavement-related-depression' is similar to that of 'non-bereavement-related depression' and therefore considered a risk factor for major depression. The current review aims to critically evaluate factors considered protective and/or contributory in depression in spousally bereaved older adults.

Method

Electronic searches were carried out on three databases. Studies were included if they examined both widows and widowers who had experienced spousal loss at 65 years or older. Studies were also required to examine depression as an outcome of bereavement as measured by a specific tool. 17 studies met the inclusion criteria.

Results

Several factors were identified from the literature with high variability between findings, which prevent clear conclusions from being made. Protective factors included aspects of personality, social support, caregiving, marital quality and religious coping. Contributory factors included high pre-loss depression levels, specific personality traits, beliefs in the afterlife and financial stress. Contradictory findings relating to caregiving, death forewarning, searching and sense-making and race prevented firm conclusions from being made.

Conclusion

The high variability between factors were discussed in terms of conceptual and methodological limitations. The implications of this study suggest the importance of retaining the individual experience of loss at the centre of bereavement intervention for this clinical population. Future research could examine the effects of spousal loss on depression levels of the current older adult cohort, thus reflecting a wider variation of relationships (including co-habiting, and same-sex).

1.1 Introduction

The introduction to this review will firstly consider the prevalence and potential impact of spousal bereavement in older adults. It will then discuss depression as a general outcome of bereavement, before exploring how this affects older adults experiencing spousal loss.

1.1.1 Spousal bereavement in older adults

In Westernised societies, widowhood is considered more likely to occur in later life, with women being at greater risk of experiencing spousal loss due to their higher life expectancy. Current statistics show that 40% of the US female population are widowed aged 65 years or older, compared to 13% of men (Federal Interagency Forum on Aging Related Statistics, 2012). In the UK, according to the Office of National Statistics (ONS, 2012), 58% of all widowed females are older than 75 years when they lose their spouse. The experience of losing a spouse in older age is fundamentally different to being widowed at a younger age, due to a number of reasons. Wolff and Wortman (2005) argued that the loss of long-term relationships,

characterised by high levels of interdependence and dependence make spousal bereavement difficult. In modern society, older couples have become more dependent on each other for support as a consequence of the greater geographical distance between families. In addition, physical illness and death among peers also place further restriction on the availability of social support. Thus losing a spouse can be associated with other losses, such as the surviving spouse's independence, which can be compounded by increasing physical health complications suffered over time (Wolff & Wortman, 2005).

1.1.2 Depression as a bereavement outcome

Over the years, depression or depressive symptoms has been examined in relation to the multiple effects of bereavement on mental health outcomes (Zisook & Shuchter, 1991; Zisook, Shuchter, Sledge, Paulas, & Judd, 1994; Stroebe, Schut, & Stroebe, 2007). Distinguishing depression as separate from other responses to bereavement, such as grief, has been problematic for researchers and clinicians alike. Differentiating between a 'normal' grief reaction and the onset of a more pathological response to loss is complex; this is due to the overlay of symptoms (sadness, insomnia, fatigue, and lack of interest and motivation) between grief and depression (Wakefield, Schmitz, & Baer, 2011). In their review Stroebe et al. (2007) mentioned studies which have identified grief and depression as being separate but related clusters of reactions to the bereavement experience.

Numerous studies have examined the extent to which minor and/or subsyndromal depression and/or bereavement-related depression (BRD) should be considered a part of the 'normal' grief reaction (Zisook, Paulus, Shuchter, & Judd, 1997; Kendler,

Myers, & Zisook, 2008). In their review Zisook et al. (1997) argued that there are inherent similarities between BRD and standard major depression, therefore those experiencing BRD may be vulnerable to more serious episodes of depression following bereavement. Kendler et al. (2008) supported this finding and confirmed a number of marked similarities between BRD and non-BRD including the duration, frequency and clinical severity of the depressive episode. The same study also identified that women and older adults seemed more likely to experience BRD (Kendler et al., 2008). The importance of understanding BRD as a potentially problematic experience, was reflected in the decision to remove the 'bereavement exclusion' criteria from the most recently published DSM V (American Psychiatric Association (APA), 2013). Clinicians are now required to use their judgment and caution in differentiating whether those recently bereaved are experiencing 'normal grieving associated with a significant loss', or symptoms suggestive of a major depressive disorder (APA, 2013).

1.1.3 Bereavement-Related-Depression in older adults

Estimates of the UK population state that there are currently 11 million people aged 65 or over in the UK (ONS, 2014); this accounts for a large percentage of the entire UK population (approximately 16%). According to the ONS (2013), of the 19% overall UK population found to have had some level of depression (and/or anxiety), a higher proportion of adults over 80 years old were affected.

The presence of depressive symptoms in older adults is often used as a barometer for assessing general well-being and mental health. Emptage, Sturm and Robinson (2005) suggest that this is due to the association between depressive symptoms and

other difficulties, such as increased functional disability and physical illness. Furthermore, the known associations between depression and increased morbidity and mortality suggest that the consequences of depression are serious for this cohort. Indeed suicide rates in people over 65 remain higher than those in younger age categories (Fiske, Loebach Wetherall, & Gatz, 2009).

Research has shown that a number of risk factors, such as living alone and dissatisfaction with living accommodation, are associated with depression in older adults (Wilson, Mottram, & Sixsmith, 2007). In their review Cole and Dendukuri (2003) also found that bereavement was reported to be among four other significant risk factors for older adults developing depression. Jozwiak, Preville and Vasiliadis (2013) found 39% of a sample of older adults were experiencing BRD. They also found no significant difference between the reported symptomatology of those experiencing BRD with those diagnosed with non-BRD; however those with BRD were less likely to obtain the help of services or be treated with antidepressant medication (Jozwiak et al., 2013). These findings were consistent with other research suggesting that subsyndromal and minor depression in those who had suffered spousal bereavement could be considered as risk factors in the later development of a major depressive disorder (Zisook et al., 1997).

1.1.4 Rationale

An increasing population of older adults in the UK, and other Westernised countries signifies a necessity to understand their difficulties as being separate from those of younger generations. Recent reviews (Wolff & Wortman, 2005; Stroebe, Schut, & Stroebe, 2007) have sought to elucidate different aspects of the bereavement

experience; however, none in the recent literature has focused solely on depression or depressive symptoms as a bereavement outcome for spousally bereaved older adults. For those who lose a spouse in older age, depression is frequently experienced as a bereavement-related outcome of that loss (Wolff & Wortman, 2005). However, the likelihood of this occurring in the first instance, continuing and/or worsening over a longer period of time may be influenced by a number of different factors. The aim of this review is to consider the clinical implications of these factors for the service provision of older adult mental health and/or bereavement services, thus helping those experiencing depression as a direct consequence of spousal bereavement.

1.1.5 Aims:

- To outline and critically evaluate the empirical evidence regarding contributory and protective factors in bereavement-related depression for older adults who have experienced the loss of their spouse.
- To identify the gaps in this literature and consider how future research could be carried out to address these gaps.

1.2 Method

1.2.1 Operational Definitions:

Depression and/or depressive symptoms following bereavement

Current literature demonstrates that bereavement-related outcomes, following the death of a spouse, encompass a wide pattern of responses such as cognitive

disorganisation, dysphoria, health deficits and disruptions in both social and occupational functioning (Bonanno & Kaltman, 2001).

For the purposes of this review, depression and/or depressive symptoms was operationalised as:

- i) An outcome of the bereavement experience as separate from other potential aspects of the grief experience (i.e. anxiety, grief, complicated grief).
- ii) A broad/global measure of psychological well-being/adjustment as measured pre and/or post bereavement.

Older adult

The aging process is argued as being subjected to the constructions by which society makes sense of old age (Gorman, 1999); perhaps for this reason, there is no universally agreed definition of the term 'older adult'. In many developed countries, chronological time is used to determine retirement age, which is often defined as 60-65 years. According to the ONS (2014) 73% of adults aged between 65 and 69 consider themselves as being in 'later life'. For the purposes of this review, older adults are therefore classified as those who are 65 years or older.

Spousal loss

Spouse is defined as husband/wife, considered in relation to their partner (Oxford Dictionary, 2015a). Conjugal is defined as relating to marriage, or the relationship between married couples (Oxford Dictionary, 2015b). For the purposes of this

review, spousal (or conjugal) loss was operationalised as the loss of a married partner due to death.

1.2.2 Inclusion/Exclusion Criteria

Table 1: Inclusion/Exclusion Criteria:

Inclusion Criteria	Exclusion Criteria
<ul style="list-style-type: none">• Adults aged 65 years or older• Participants had suffered spousal bereavement at 65 years or older• Articles included depression or depressive symptoms as an outcome of bereavement measured by a specific tool• Articles studying the impact of bereavement on men and women• Only peer reviewed articles• The article was in English	<ul style="list-style-type: none">• Studies detailing only presence and/or prevalence of depression• Studies focusing on only men (widowers) or women (widows)• Articles predating 1995 (in order to ensure the literature was focusing on information relevant to current understandings of the subject of review)

1.2.3 Search strategy

Searching for relevant articles began in October 2014 and ended in February 2015. Whilst PsychInfo, Medline and Web of Knowledge were the three main databases used, the Cochrane database was also searched for existing literature reviews. Full articles were obtained if their abstracts met the inclusion criteria and further articles were identified from the reference lists, in addition to using the cited function on relevant databases. The primary search was performed by using the following search terms: 'Bereavement OR grief', 'depression OR depressive symptom*' and 'older adult OR elderly OR old age* OR elderly' and 'spous* OR widow* OR conjugal'. (See Figure 1 for search strategy).

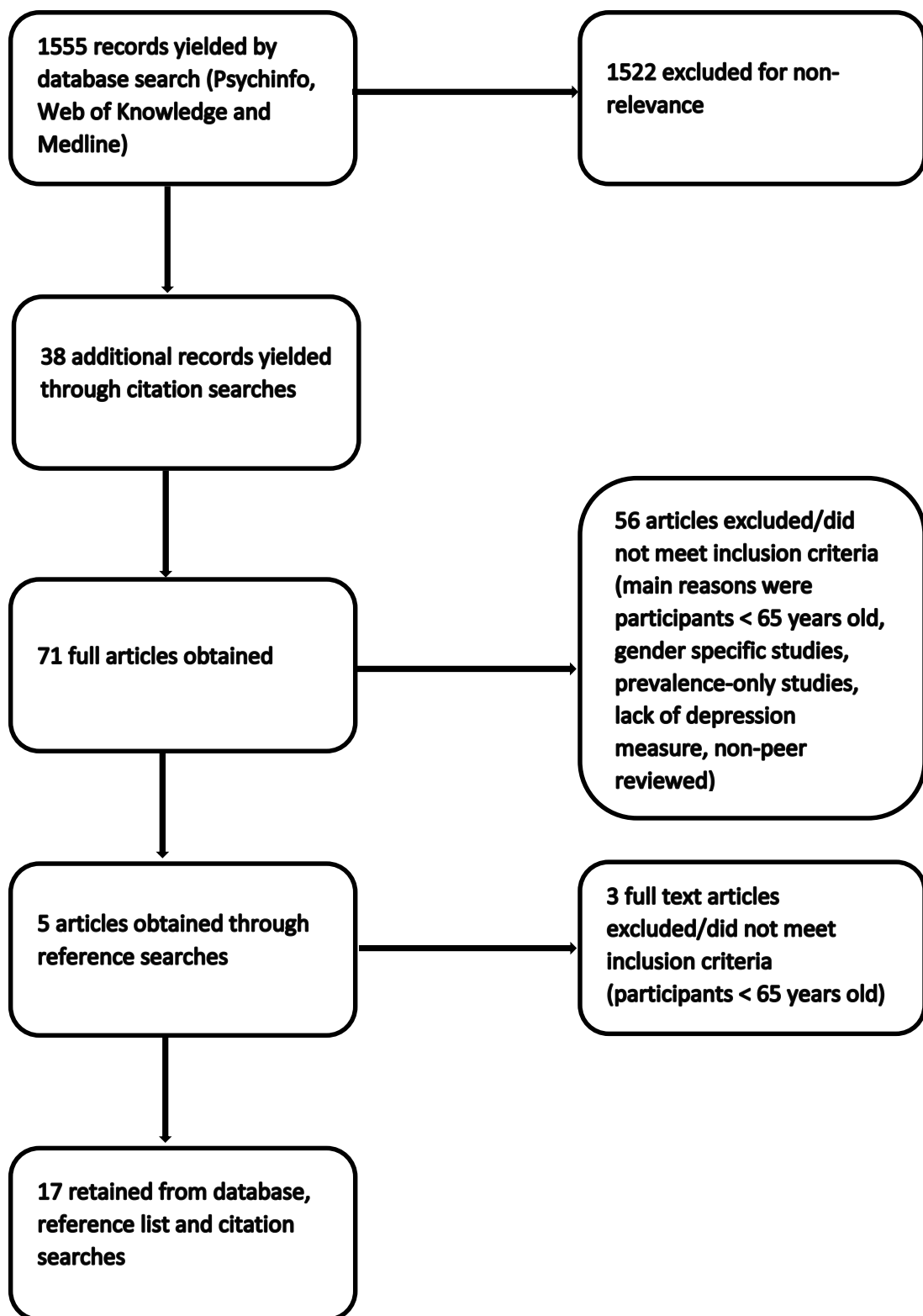


Figure 1: Search Strategy

1.2.4 Quality Assessment

The systematic search yielded articles based on studies, all of which used a longitudinal methodological design. For this reason, the framework used to assess quality was based on the 33 item checklist developed by Tooth, Wain, Bare, Purdin and Dobson (2004). Each criterion was rated as yes, partially, not at all met/unknown and was awarded either 2, 1 or 0 point respectively. See Appendix B for the full checklist. Articles were rated as 'high' in quality if they obtained overall ratings of 44 or above, 'medium' if they scored between 22 and 43, and 'low' if they scored less than 22. All papers were included in the review, regardless of their score, with comments relating to quality scores made where relevant.

1.3 Results

The aim of this review was to outline articles that had studied the effects of protective and/or contributory factors on depression/depressive symptoms in older adults who had been bereaved of their spouse. Factors were considered protective if they appeared to prevent the development and/or continuation of depression following bereavement, and contributory if their presence or absence predicted worse outcomes for the surviving spouse. All factors are presented through a series of emerging, and often interrelated, themes. These were similar to those presented by Wolff and Wortman (2005) in their review of the psychological consequences of bereavement in older adults.

The 17 papers included in this review used a quantitative methodology and were based on longitudinal studies carried out in the USA. Of the 17 papers reviewed, 15 draw their data from the Changing Lives of Older People's Study (CLOC), a multi-wave prospective study carried out in the USA between 1988 and 1993. All studies used an adapted version (9, 10 or 11 item) of the Center for Epidemiologic Studies Depression (CES-D) Scale (Radloff, 1977). See Table 2 for details of papers and Appendix C for a description of each longitudinal study. Unless otherwise stated, the paper under discussion has used data from the CLOC study.

Table 2: Selected Papers for Review (Chronological Order)

Author, Year	Study Aims (specific to depression)	Participant Information (age/ N/ ethnicity/ gender)	Measures (relevant to depression and associated predictor variables)	Main findings (re depression/depressive symptoms)	Quality Rating
Carr et al. (2000)	Examined whether psychological adjustment (according to measures of depression and anxiety) is affected by three dimensions of the marital relationship: warmth-closeness; conflict and instrumental dependence	N = 215 women N = 75 men Average age: 73.59	Analysis comprising data extracted from interviews carried out pre-loss (baseline) and six months post-loss. <i>Standardised measures:</i> CES-D 9- item version Dyadic Adjustment Scale (Spanier, 1976) to assess dimensions of marital domains (warmth-closeness, instrumental dependence and conflict). <i>Non-standardised measures:</i> Physical health pre-loss	Widowed persons had significantly more depressive symptoms than married controls at six months post loss ($M=0.408$, $SD=1.22$, $p\leq.001$). However the effect of bereavement on depressive symptoms does not decline when marital quality indicators are included into the analysis. This was not the case for anxiety or yearning, which were both affected significantly by marital quality.	High
Carr, House, Wortman, Nesse and Kessler (2001)	Examined the relationship between death forewarning and widowed person's psychological adjustment (according to measures of depression and anxiety) six and 18 months after loss; to assess whether and how the relationship between death	N = 151 women N = 59 men Average age: 69.43	Analysis comprising data extracted from interviews carried out pre-loss (baseline), and six and 18 months post-loss. <i>Standardised measures:</i> CES-D 9- item version <i>Non standardised measures:</i> Warning time prior to death	Death forewarning regardless of how it was operationalised was unrelated to depressive symptoms, even when counterbalancing/suppressor variables were added. Gender differences in the effect of forewarning were not significant for depressive symptoms. Sudden spousal death does not have far-reaching	High

	forewarning and widowed person's well-being differs for men and women. In addition it evaluates the extent to which the effect of death forewarning is mediated or suppressed by the death context characteristics.		Death context (age of spouse, dichotomous variables relating to care and/or whether spouse was in nursing home prior to death)	deleterious effects on mental health, except for increased intrusive thoughts during the first six months post-loss.	
Schulz et al. (2001)	Examined prospectively the effects of spousal death on depressive symptoms, antidepressant use, health risk behaviours and weight as a function of involvement in caregiving prior to death.	N = 96 women N = 33 men Average Age 80.1 years White 89.9%	<p>Longitudinal (prospective) study. Sample drawn from the Caregiver Health Effects Study (CHES), an ancillary study of the Cardiovascular Health Study (CHS). Analysis comprised of data from interviews carried out with participants who reported being widowed at waves two, three (annual interviews) and four (two years after wave three).</p> <p><i>Standardised measures:</i> CES-D 10 item version Measures of pre-loss depression were taken at the interview preceding loss, and compared with the interview immediately succeeding the loss.</p> <p><i>Non standardised measures:</i> Baseline Prevalent Cardiovascular Disease Pre-bereavement Caregiver Status</p>	<p>There was a significant increase in depressive symptoms between pre and post-bereavement measures for the non-caregiver group $F(1,116) = 14.33, P < .001$, and the care-giver no strain group $F(1,116) = 4.35, P = .04$. The caregiver-strain group remained unchanged pre and post bereavement.</p> <p>Race was the only covariate yielding a significant effect; African-Americans had significantly lower depression than Whites ($p = 0.2$) (pre and post-bereavement)</p>	Medium

			Anti-depressant medication use Health Risk Behaviours		
Bonnano et al. (2002)	To operationally define chronic grief and resilience from other bereavement patterns following spousal loss. Evaluating hypotheses relating to antecedents of chronic grief and absence of grief by identifying pre-loss predictors.	N = 180 women N = 25 men Average age of sample: 72 years	Analysis comprising data extracted from interviews carried out pre-loss (baseline), six and 18 months post-loss. <i>Standardised Measures:</i> CES-D 9 item version. Dyadic Adjustment Scale (10 items adapted version), (Spanier, 1976) Ambivalence about the spouse/marriage calculated following procedure used to measure ambivalent attitudes (adapted) Interpersonal Dependency Scale (Hirschfield, Klerman, Gouch, Barrett, Korchin, & Chodoff 1977) Dependency on the Spouse developed by author (adapted) Autonomy Scale Interpersonal NEO Personality Inventory (Costa & McCrae, 1992) <i>Non-standardised measures:</i> Confidence in own coping ability Religiosity: personal devotion, religious conservatism Introspection World view: Belief in a just world; belief in	Five patterns of bereavement were defined as: 'chronic depression', 'depressed-improved', 'chronic grief', 'common grief' and 'resilient'. Pre-loss depression predicted post-loss depression in 'chronic depressed' group $F(4,180) = 79.93, p < .0001$. Pre-loss variables associated with this group included aspects of marital relationship, neuroticism, perceived coping, world views and meaning. The 'depressed-improved' group associated with neuroticism, spouses were seriously ill prior to death, reduced instrumental support, negative evaluations and ambivalence towards spouse/marriage. The 'Chronic grief' group was associated with high dependency and interpersonal dependency, reduced instrumental support. The 'resilient group' was associated with protective worldviews	High

			personal injustice; belief in the uncontrollability of negative events; acceptance of death Context: spousal illness; caregiving; caregiving strain; perceived support from friends and relatives; perceived support from children; instrumental support from family and friends		
Carr (2004)	Examined the effects of race on depression following spousal loss. It also addresses whether white and black people experience different grief symptomatology.	(Excluding controls) N = 151 women N = 59 men 177 White 33 Black Average age 70.4	Analysis comprising data extracted from interviews carried out at baseline and six months post-loss. <i>Standardised measures:</i> CES-D 9 item version Dyadic Adjustment Scale (Spanier 1976) to evaluate marital conflict and dependence <i>Non-standardised measures:</i> Marital quality Marital duration Religiosity: Attendance and religious coping Social support: Dependence on children and social support from friends and family	Participants do not differ in terms of depressive symptoms (or anxiety) at baseline or six months post-loss. Race was not concluded as a significant predictor of depressive symptoms or anxiety. Other more specific grief outcomes were associated with race differences.	High
Carr (2004)	Examined gender difference in the desire for a romantic relationship among older widowed persons in the USA, and the psychological consequences (i.e. depression as	N = 159 women N = 59 men Average age: 70.56	Analysis comprising data extracted from interviews carried out pre-loss (baseline), six and 18 months post-loss <i>Standardised measures:</i> CES-D 11- item Dyadic Adjustment Scale (Spanier 1976) to	Widowed participants who were both interested in forming a romantic relationship and currently dating were found to have significantly lower levels of depressive symptoms (at 18 months post-loss) $p < .05$. However, the effects ceased	High

	a bereavement outcome) of having fulfilled such preferences.		<p>assess marital quality</p> <p><i>Non-standardised variables:</i></p> <p>Desire to remarry; and interest in dating</p> <p>Indicators that 'one is interested in either dating or remarriage and is dating' and 'one is interested in either dating or remarriage and is not currently dating' (measuring congruence between desire and actual establishment of romantic relationship)</p>	<p>to be significant when social economic status is controlled for, suggesting that lower depressive symptoms are due to reduced financial burden.</p> <p>The effects of fulfilled/unfulfilled romantic hopes on depressive symptoms does not differ significantly by gender.</p>	
Boerner, Wortman and Bonanno (2005)	To examined the bereavement patterns (identified previously by Bonanno et al. (2002)) from 18 to 48 months post-loss, in order to examine the stability/instability of such patterns over time.	<p>N = 83 women</p> <p>N = 9 men</p> <p>Average age: 70 years</p>	<p>Analysis comprising data extracted from interviews carried out at pre-loss (baseline) 18 and 48 months post-loss.</p> <p><i>Standardised measures:</i></p> <p>CES-D 9-item version</p> <p><i>Non standardised measures:</i></p> <p>Extent of thinking about spouse</p> <p>'Searching for meaning'</p> <p>Asking why me</p>	<p>The 'resilient' and 'common grief' groups continued to do well over time.</p> <p>Depression scores for those in the 'depressed-improved' group increased at 48 months, compared to those in the 'resilient' group. The 'chronic grief' group showed high distress compared with the 'common grief' group but this reduced by 48 months post-loss. The 'chronically depressed' group showed no indication of improvement between 18 and 48 months, and also were significantly more likely to search for meaning (at 48 months) than other groups $t(87)=-2.86, p<.01$.</p>	High

Prokos and Reid Keene (2005)	Examined surviving spouses' levels of depressive symptoms at 18 and 48 months post-loss after loss, in order to determine the impact of caregiving on survivors' well-being beyond the initial period of bereavement. The study also investigates specific characteristics of the caregiving situation including type, intensity and duration of care.	N = 149 women N = 61 men Average age: 73.66 84% White	Analysis comprising data extracted from interviews carried out pre-loss (baseline) and 18 and 48 months post-loss. <i>Standardised measures:</i> CES-D 9- item version <i>Non standardised measures:</i> Caregiving situation Caregiver stress Level of care Emotional support	At 18 months post-loss increased care-giving stress is associated with lower depression levels $\beta=-0.246, p<0.01$. Also at 18 months post-loss, greater caregiver burden was associated with higher depression $\beta=1.000, p<0.01$. However, at 48 months the situational aspects of care no longer had an ameliorative effect on depressive symptoms. At this time, being a caregiver has a positive effect on depressive symptoms $\beta=-0.355, p<0.05$, but that the situational factors associated with experience are no longer important.	High
Burton, Haley and Small (2006)	Comparing bereavement outcomes for those who have experienced their spouse dying unexpectedly with relevant subgroups of individuals experiencing expected death after caregiving	N = 170 women N = 23 men Average age 69.48 years 84.22 % Caucasian Americans; 15.78% African-American	Analysis comprising data extracted from interviews carried out pre-loss (baseline), six and 18 months post-loss <i>Standardised Measures:</i> CES-D 11- item version. Bradburn Affect Balance Scale (ABS; Bradburn, 1969) to measure overall psychological wellbeing <i>Non-standardised measures:</i> Measures of demographics and marital quality Pre-loss caregiving status (established via non-standardised measures at 6mth post-loss interview)	Depression increased significantly over time for the unexpected death group, estimate $\beta= 0.146, SE = 0.042, p=0.001$ while other groups remained stable. Highly stressed caregiving was not associated with improvements in well-being post-loss. Unexpected death was postulated as a more important predictor of change in wellbeing after bereavement than the nature of the caregiving experience.	Medium

			Social engagement Physical health		
Brown, Brown, House, and Smith (2008)	Examined how social support provided to others will show evidence of stress buffering. Social support given to others is therefore analysed in terms of its success in predicting stress-related outcomes (i.e. depression).	N = 180 females N = 25 males Average age: 76.50 years. 85.1% Caucasian 14.9% African-American	Analysis comprising data extracted from interviews carried out pre-loss (baseline), six and 18 months post-loss. <i>Standardised measures:</i> CES-D 11-item version 'The stress response': the grief composite derived from the mean of three standardised subscales from the Bereavement Index <i>Non standardised measures:</i> 'Help index predictor' devised as a non-standardised measure to reflect participants' perception of instrumental support they provide to others	Findings support the 'late stress buffering hypothesis' – that support given <i>after</i> the bereavement event has been perceived as stressful facilitates adjustment. For participants with high levels of grief, reports of helping others at 6 months post-loss predicted a significant decline in depressive symptoms in the successive year, $B = -.05$, $SE = .02$, $p < 0.05$. Additional findings were that greater caregiving hours predicted worse depressive symptoms at six months post-loss when helping was low $B = .199$, $p < .05$	High
Reid Keene, and Prokos (2008)	Examined how the situational aspects of spousal caregiving relate to survivors' depressive symptoms six months into widowhood. The relief model is explicitly tested, thus suggesting that depressive symptoms would be lower in caregivers compared to non-caregivers 6 months post loss. Positing	N = 137 women N = 52 men 189 White Average Age: 70 years	Analysis comprising data extracted from interviews carried out pre-loss (baseline) and 6 months post-loss. <i>Standardised measures:</i> CES-D11 item version <i>Non-standardised measures:</i> Caregiving situation – caregiver to spouse; caregiver stress; providing personal care; hours per week.	There was no significant difference in depression for caregivers and non-caregivers at six months post-loss. Situational aspects of caregiving were incorporated into the analysis, which found that caregiving for longer than six months had a significant negative effect on depressive symptoms at 6 months post loss compared to non-carers ($\beta = -1.16$, $SE = 0.56$, $p \leq 0.05$) and carers of less than six	High

	negative relationships between intensive care and depressive symptoms during bereavement.			months ($\beta=0.83$, SE 0.26, $p\leq 0.01$) . No associations were found between other aspects of the caregiving situation (stress, type of care and hours spent caring).	
Taylor, Kuchibhatla, Ostbye, Plassman and Clipp (2008)	Examined whether there are gender differences in how spousal caregiving influences caregiving depressive symptoms, and whether bereavement or admission of care recipient to a nursing home influence this.	<p>N = 984 women</p> <p>N = 984 men</p> <p>Average age 72.8 years (women); 76.4 years (men)</p> <p>9.9% 'non-white'</p>	<p>Longitudinal study based on the Health Retirement Study.</p> <p><i>Standardised measures:</i> CES-D – version is not mentioned.</p> <p><i>Non standardised measures:</i> Caregiving arrangement – four levels based on whether participants provided care or not. This was entered as a time varying covariate. Time since death (0-3 months, 4-15 months, >15 months)</p>	Upon bereavement depressive symptoms initially rose substantially (0-3 months) ($M=4.67$, SD 0.44, $p<0.001$). At 15 months depressive symptoms were still significantly elevated compared to pre-loss levels ($M= 2.53$, SD 0.17 to $M=2.75$, SD 0.19, $p<0.001$), but were substantially lower than the immediate bereavement period. 'Harm due to caregiving in form of increased depressive symptoms does not appear to be long-lasting' (pg 105)	High
Coleman and Neimeyer (2010)	Examined how searching and sense-making at six, and 18 months post-loss are related to each other and to grief, depression and well-being following late life spousal bereavement.	<p>N = 206 women</p> <p>N = 33 men</p> <p>Average age: 72.84 years (Wave 1)</p> <p>Caucasian 83%</p>	<p>Analysis comprising data extracted at six and 18 months post-loss.</p> <p><i>Standardised measures:</i> CES-D 9- item</p> <p><i>Non standardised measures:</i> Searching for meaning Sense making</p>	When depressive symptoms at six months were controlled for, searching significantly increased depression at 18 months but only for participants who were categorised at 'higher-levels of sense-making' $\beta=.604$, $p<.001$. This interaction was rendered non-significant after responses from two participants (reporting searching 'often' and 'making a	High

		African American 16% Hispanic/Latino 1%		great deal' of sense) from the analysis $p=.418$.	
Pai and Carr, (2010)	Examined whether the effects of spousal loss on older adults' depressive symptoms is moderated by personality traits. It goes on to explore whether patterns are based on death being unexpected or anticipated.	N = 159 women N = 51 men Average age: 69.59 84% white	Analysis comprising data extracted from interviews carried out pre-loss (baseline) and 6 months post-loss. <i>Standardised measures:</i> CES-D 9- item version Personality Inventory (NEO PI-R) (Costa & McCrae, 1992) <i>Non standardised measures:</i> Widowhood status and extent to which one was forewarned Perceived financial strain Relocation Spousal caregiving (removed after preliminary analysis) Support from children Support from friends and relatives	The effects of widowhood on depressive symptoms differs based on the individual's level of extraversion $\beta=-.287$, $p<.05$ and conscientiousness $\beta=-.233$, $p.05$, which are significant effects after adjusting for secondary stresses and coping resources. However, the protective effects of extraversion and conscientiousness are modest, and only account for 5% of the variance in depressive symptoms. Furthermore, losing a spouse suddenly significantly reduces the protective effects of extraversion $\beta=.432$, $p<0.05$.	High
Ha, Ingersoll and Dayton (2011)	Examined how widowed persons' frequency of contact with friends and relatives affects their depressive and grief symptom at six months post-	N = 151 women N = 58 men	Analysis comprising of data extracted from interviews carried out pre-loss (baseline) and six months post-loss.	Frequent social contact is associated with lower levels of depressive symptoms $B=-.24$, $p\leq 0.01$; however, this effect ceases to be significant when contextual factors are included, suggesting that the context of	High

	loss. It also addresses whether the effects of social contact are contingent upon the degree of emotional support received, and congruence between widowed persons' preferred and actual levels of social contact.	Average age: 73.5 Asian and Hispanic populations were not included in the dataset	<i>Standardised measures:</i> CES-D 9 - item version <i>Non standardised measures:</i> Frequency of contact with friends and relatives Social support from friends and relatives Congruence between preferred and actual level of social contact	relationships is more important than the amount of contact. Higher levels of social support were significantly associated with lower levels of depressive symptoms $B=0.25, p\leq 0.01$. Congruence between preferred and actual level of support is associated with lower levels of depressive symptoms $B=-.43, p\leq 0.01$.	
Galatzer-Levy, and Bonanno, (2012)	This study used Latent Growth Method to examine the prospective trajectories of bereavement from pre-loss to 48 months, anticipating a heterogeneous pattern of response including 'resilience', 'chronic grief', 'chronic depressed', 'recovery' and 'depressed-improved'; and that 'chronically-depressed' and 'resilience' trajectories will remain stable. Covariates including personality traits (low levels of emotional stability), age, financial stress and poor health will be predictive of	N = 269 women N = 32 men Average age at 6 months post-loss: 72 years	Analysis comprising data extracted from interviews carried out pre-loss (baseline), and 6, 18 and 48 months post-loss <i>Standardised measures:</i> CES-D: 9 item version Personality Inventory (NEO PI-R) <i>Non standardised:</i> Financial stress Functional health index	All grief trajectories, with the exception of 'recovery' were found to be stable. Financial stress predicted greater levels of depression after loss even among groups who did not show high levels of depression throughout bereavement. 'Depressed-improved' and 'chronic-depression' classes displayed lower scores on emotional stability, which is associated with higher trait neuroticism (thus less adaptive and more pathological).	High

	higher levels of depression within each class following loss.				
Carr and Sharp (2013)	Examined the beliefs about how both the existence and nature of the afterlife affect the bereavement process. Evaluating depressive symptoms as an aspect of psychological adjustment to loss among older adults, and the extent to which these patterns may persist in the shorter and longer term (six and 18 months post-loss respectively).	N = 159 women N = 51 men Average age: 70.56	Analysis comprising data extracted from interviews carried out pre-loss (baseline), and six and 18 months post-loss. <i>Standardised measures:</i> CES-D 9 item version Dyadic Adjustment Scale (Spanier, 1976) to assess marital quality Religious Coping Scale (Pargament et al., 1988) <i>Non standardised measures:</i> Afterlife beliefs: whether one believes in the afterlife, belief that one be reunited in the afterlife and belief that people who suffer unjustly in this life will be rewarded in the afterlife	Participants who believe in an afterlife yet do not believe that loved ones are reunited reported higher depressive symptoms at six months post-loss $\beta=1.09$, $p\leq.01$. Though this effect size declined considerably at 18 months post-loss $\beta=0.69$, $p\leq.05$. The study also found that religious coping was significantly and negatively related to depressive symptoms $\beta=-.17$, $p\leq.10$.	High

1.3.1 Pre-loss depression as a predictor of post-loss depression

Three studies explicitly posited the presence of high pre-loss levels of depression as leaving individuals more vulnerable to experiencing continued depression after bereavement. Categorisation methods were used by Bonanno et al. (2002) to compare pre- and post- depression scores of a sample of spousally bereaved older adults; these defined five bereavement patterns over the course of 18 months post-loss. 'Chronic-depressed' and 'depressed-improved' patterns were characterised by high pre- with (continuing) high and low post-loss depression scores respectively. The 'chronic grief' pattern was characterised by low pre- and high post-loss depression (and grief) scores. The 'common grief' pattern was characterised by low pre- and high, though declining, post-loss depression scores. The 'resilient' pattern was characterised by low pre- and low post-loss depression scores (Bonanno et al., 2002). Boerner et al. (2005) used repeated measures analysis of variance to examine the same patterns between 18 and 48 months post-loss and Galatzer-Levy and Bonanno (2012) supported these distinctions in their study using Latent-Class-Growth-Analysis (LCGA). Whilst the 'depressed-improved' pattern was characterised by high pre- and low post-loss depression scores by all three studies, Boerner et al. (2005) reported that depression levels at 48 months increased, whereas Galatzer-Levy and Bonanno (2012) found that depressive symptoms remained stable for this group at this time point. The comparative strength of this latter study was that LCGA used best-fit-models to identify the parameters and predictor variables of each bereavement pattern as opposed to relying on post-hoc methods.

The protective and/or contributory predictor variables of the bereavement patterns are explained under different headings. In consideration of the likely influence of pre-loss depression measures on post-loss bereavement outcomes, all but one of the studies in this review controlled for this potentially confounding variable in their analyses.

1.3.2 Personality factors

Three studies examined whether any of the Big Five personality traits (extraversion, neuroticism - emotional stability, agreeableness, openness to experience and conscientiousness) were associated with post-loss depression following spousal loss.

After establishing a significant increase in depressive symptoms between pre- and post-loss, Pai and Carr (2010) estimated ordinary least squared (OLS) regression to explore whether the effects of spousal loss on depressive symptoms varied according to personality traits. They found that the effects of widowhood on depressive symptoms differed only on the individual's levels of extraversion and conscientiousness. Bereaved participants who demonstrated higher levels of extraversion and conscientiousness at six months post-loss had significantly lower depressive symptoms ($\beta = -.287$, $p < .05$ and $\beta = -.233$, $p < .05$ respectively); this remained the case after controlling for coping resources and secondary stresses (i.e. perceived financial strain and relocation). However, by incorporating the contextual factor of death forewarning, the protective effects of extraversion were reduced in participants whose spouse suffered a sudden death (Pai & Carr, 2010).

Bonanno et al. (2002) and Galatzer-Levy and Bonanno (2012) also used specific personality traits as predictive variables in characterising the different bereavement

patterns following spousal loss. Both studies identified that individuals experiencing high pre-loss depression scores were associated with higher neuroticism or lower emotional stability (associated with high trait neuroticism), and thus considered less adaptive in their ability to cope with the bereavement experience (Bonanno et al., 2002; Galatzer-Levy & Bonanno, 2012).

The above studies support the notion that personality traits are implicated in the variability in depressive symptoms in older adults experiencing spousal loss. However, one of the limitations of using regression analysis is difficulty in ensuring that all appropriate variables have been included in the data. Given the influence of death forewarning in terms of how far extraversion could be considered protective in post-loss depression, it is possible that the effects of other potentially influential variables were neglected due to their omission from analysis. The finding that the moderating effects of both extraversion and conscientiousness only accounted for five percent of the variance in depression scores at six months post-loss (Pai & Carr, 2010), supports further examination of other potentially influential factors.

1.3.3 Contextual factors

Two contextual factors were included in this review; caregiving and death forewarning.

Caregiving

Caregiving was examined by six studies. The disparity between findings suggests a complex picture regarding whether aspects of caregiving can be considered protective and/or contributory to post-loss depression.

Three studies considered the effects of 'caregiver stress' on post-loss depressive symptoms (Prokos & Reid 2005; Burton et al., 2006; Reid Keene & Prokos, 2008). Whilst Reid Keene and Prokos (2008) found no significant effect of 'caregiver stress' on depressive symptoms at six months post-loss, caregiving for a period of six months or longer was associated with increased depressive symptoms at this time $\beta=-1.16$, SE 0.56, $p\leq 0.05$. Burton et al. (2006) also found no association between high 'caregiver stress' and improved depression levels at 18 months post-loss. However, in contrast to these findings, Prokos and Reid Keene (2005), found that high 'caregiver stress' was associated with lower depression scores at 18 months post-loss $\beta=-0.246$, $p<0.01$. The contradictory nature of these findings could be due to the lack of consensus regarding conceptualisation of these particular aspects of the caregiving situation. This is reflected in the lack of psychometric validity and reliability of these caregiver variables. A further consideration is the utilisation of retrospective accounts of the caregiving experience in these studies; thus variables are vulnerable to subjective positive and/or negative bias.

Three studies considered 'caregiver burden' or 'caregiver strain' or 'caregiving hours' on depressive symptoms, (Schulz et al., 2001; Prokos & Reid Keene, 2005; Brown et al., 2008). Prokos and Reid Keene (2005) found that higher levels of 'caregiver burden' (measured by hours spent per week caring and type of care) was associated with increased depression at 18 months post-loss $\beta=1.000$, $p<0.01$. Brown et al. (2008) also found that when combined with high grief and low helping behaviours towards others (post-bereavement), high caregiving hours was associated with increased depression at 18 months, $B=.199$, $p<.05$. However, Schulz et al. (2001) found that depression scores for those in the 'caregiver-strain' group remained

unchanged compared to those in the 'non-caregiver' and 'caregiver-no-strain' groups whose scores were significantly higher post-loss ($F(1,116) = 14.33, P < .001$ and $F(1,116) = 4.35, P = .04$ respectively). A comparative strength of Schulz et al.'s study (2001) was that data measuring 'caregiver strain' was obtained prior to spousal loss. However, the same study was limited in terms of its lack of clarity regarding timings of data collection (in relation to the loss), a relatively small sample size and omission of potentially relevant covariates (i.e. social support and/or marital quality). Such limitations reflected the 'medium' quality score obtained by the study. The contrast between the findings reported in these studies could also reflect the utilisation of different longitudinal data sets. This is important in consideration of how far any of the studies included in this review can be truly generalizable to the whole population.

As opposed to reporting the effects of specific aspects of the caregiving situation (i.e. stress, burden, strain, duration) three studies provided general findings in relation to caregiving in itself on post-loss depression. By extending their analysis to include data at 48 months post-loss, Prokos and Reid (2005) found that the experience of being a (spousal) caregiver in itself had a positive effect on depressive symptoms at this time $\beta = -0.355, p < 0.05$, and that specific aspects of the caregiving situation were no longer important. However, small sample size at the 48 month point may confound these findings. Taylor et al. (2008) found that bereavement was associated with a significant increase in depression at 0-3 months ($M = 4.67, SD 0.44, p < 0.001$), but that by 15 months post-loss, depression scores had declined to near pre-bereavement levels for all participants (including non-caregivers) ($M = 2.53, SD 0.17$ to $M = 2.75, SD 0.19, p < 0.001$). The study therefore concluded that 'harm due to caregiving in the form of increased depressive symptoms does not appear to be long-lasting' (Taylor

et al., 2008, pg 105). Furthermore, whilst not specifically conceptualising 'caregiver stress', 'caregiver strain' or 'caregiver burden', Bonanno et al. (2002), used chi-square analysis to determine that all participants categorised as 'depressed-improved' had seriously ill spouses prior to their death, thus proposing that the decline in depressive symptoms post-loss was associated with release from the caregiving situation.

Definitive conclusions regarding the protective/contributory nature of caregiving in depression following spousal loss in older adults cannot be made due to the contradictory nature of findings. Thus consideration is given to the potential influence of other factors.

Death forewarning

Death forewarning as a protective/contributory factor in depression following spousal loss was considered by three studies. Again the findings were disparate and explained in terms of methodological and conceptual limitations.

Carr et al. (2001) used estimates of OLS regression to predict effects of death forewarning on depression. 'Forewarning' was operationalised as up to 6 months of warning prior to death, whereas 'sudden death' applied to participants who reported having had no warning/minutes prior to death. The results showed that forewarning was unrelated to depressive symptoms at six or 18 months post-loss (the effects remained after controlling for other potentially influential variables) (Carr et al., 2001). Whilst this study incorporated a number of potentially confounding variables in its analysis, others, such as marital quality, were not included. Furthermore, consideration must be given to the possibility that the presence of grief itself (at six months post-loss) may have affected the accuracy of participants' retrospective

reports regarding the context of their spouses' death. Burton et al. (2006) compared the effects of 'unexpected spousal death' with expected death after caregiving on post-loss depression. In contrast to Carr et al. (2001), they reported a significant increase in depression over time for participants who had experienced 'unexpected spousal death' $\beta = 0.146$, $SE = 0.042$, $p = 0.001$ (Burton et al., 2006). The disparity of findings between the two studies may be due to differences between how 'unexpected spousal death' and 'forewarning/sudden death' were conceptualised. A related limitation of the latter study was also the assumption that individuals who provided care to their spouses expected their death. Such limitations are reflected in the medium quality score attributed to the study carried out by Burton et al. (2006).

Pai and Carr (2010) also examined the effects of death forewarning on depressive symptoms post-loss. However, this is considered in relation to the moderating effects of personality on death forewarning (less than six months forewarning, and extended forewarning). The findings of this study support those of Burton et al. (2006), in that there was an effect of death forewarning on depression levels at six months post-loss. Extraversion was associated with significantly lower levels of depression if the loss was expected $\beta = -.383$, $p < .001$, and this effect remained after controlling for secondary stressors. However, none of the personality traits were protective against depression when the loss was sudden. The moderating effects of extraversion (for those who expected loss) declined by nearly 25% after controlling for emotional support, thus highlighting the importance of considering social support as potentially protective against depression following spousal loss.

1.3.4 Personal Resources and Coping

In addition to receiving and providing social support, other potentially protective/contributory factors relating to personal resources and coping were identified as afterlife beliefs, meaning-making and social economic status (SES).

Receiving Social support

Whilst the majority of studies have included social support as a confounding variable, only two studies examined aspects of social support as potentially protective against post-loss depression (Bonanno et al., 2002; Ha et al., 2011). Ha et al. (2011) used estimates of OLS regression to show that contextual factors associated with social contact exerted a greater effect on post-loss depression levels than the frequency of social contact (from friends and relatives) alone. Higher levels of social support (i.e. how much the surviving spouse felt cared for and supported) and congruence between preferred and actual levels of support were associated with lower levels of depression at six months post-loss $B=0.25$, $p\leq 0.01$ and $B=-.43$, $p\leq 0.01$ respectively (Ha et al., 2011). These findings are supportive of specific aspects of social support protecting against the effects of depression. However, limitations included combining two separate elements of social support – friends and relatives, into one moderating variable. Furthermore, restricting the study to examining effects at only six months post-loss, prevented authors from exploring effects of social support over a longer period. This was also the only study that did not include pre-loss measures of depression as a confounding factor, thus findings may be vulnerable to inaccurate interpretation.

Social support as a predictor variable in the characterisation of bereavement patterns was considered by Bonanno et al. (2002). Reduced instrumental support from others was associated with individuals following the 'chronic grief', 'chronic depressed' and 'depressed-improved' patterns $F(4, 80) = 3.17, p < .05$. This finding therefore suggests instrumental support is protective for some individuals, following the loss of their spouse.

Providing social support

In contrast to studies considering the effects of receiving social support, one study examined the effects of providing social support to others on depression levels following spousal bereavement. Brown et al. (2008) conceptualised this type of social support as 'helping behaviours' (providing instrumental help) following bereavement. They found that for participants with high levels of grief, reports of helping others at six months post-loss predicted a significant decline in depressive symptoms in the following year $B = -.05, SE = .02, p < 0.05$ (Brown et al., 2008). This finding was used to support the 'late stress-buffering hypothesis', suggesting that helping behaviours facilitate post-loss adjustment *after* the individual has perceived the bereavement event as stressful (Brown et al., 2008). However, the conceptualisation of helpful behaviour, which did not include perceived emotional support, may limit how far this can be considered a protective factor. Furthermore the study was also unable to account for all variables of physical health, which could impact participants' ability to provide instrumental support.

Coping resources

Two studies considered the extent to which different coping resources were potentially protective/contributory in depression levels following older adult spousal loss (Bonanno et al, 2002; Carr & Sharp, 2013). Carr and Sharp (2013) employed estimates of OLS regression to examine the effects of older adults' beliefs about both the existence and nature of the afterlife on post-loss depression at six and 18 months post-loss. Participants who believed in an afterlife, yet did not believe that loved ones are reunited, reported higher depressive symptoms at six months post-loss $\beta=1.09$, $p\leq.01$; however, this effect reduced considerably at 18 months $\beta=0.69$, $p\leq.05$. Of the additional variables included in the analysis, religious coping was reported as significantly and negatively related to depressive symptoms at six and 18 months post-loss $\beta=-.17$, $p\leq.10$. However, even after religious coping was controlled for, the effects of the belief that the afterlife exists but reunification is not possible remained consistent. These findings suggest that believing one's spouse continues to live on in the afterlife but that one will never see them again is highly distressing (Carr & Sharp, 2013). The study also demonstrates the complexity of religiosity as a construct which has elements that can be both protective and contributory. However, afterlife beliefs and confounding factors accounted for only 16% of the overall variability in psychological adjustment to loss (due to poor model-fit for the afterlife belief indicators).

Personal religious devotion and personal religious conservatism were considered pre-loss predictor variables by Bonanno et al. (2002). Pairwise comparisons showed no relationship between these variables and depression. However, the pre-loss

predictor variable of 'perceived coping ability' (also conceptualised as a coping resource) showed that participants in the 'chronically-depressed' group had a lower perceived coping ability than all other groups. This suggested that assessing perceived coping ability in highly depressed individuals may predict which individuals are more likely to remain depressed post-loss (Bonanno et al., 2002). One of the strengths of this study is that all pre-loss predictor variables had internal consistency (according to Chronbach's $\alpha \geq .60$) and were therefore reliable.

Meaning and sense-making relating to loss

Three studies considered the effects of searching for meaning and/or trying to make sense of loss on depressive symptoms in older adults following spousal bereavement (Bonanno et al., 2002; Boerner et al., 2005; Coleman & Neimeyer, 2010). Once again, conflicting/divergent/contradictory results between studies meant firm conclusions could not be made regarding the extent to which these aspects of personal resources were protective/contributory in post-loss depression.

Coleman and Neimeyer (2010) used regression analysis to assess the effect of 'searching for meaning' and 'sense-making' on adjustment to bereavement at six and 18 months post-loss. A tenuous association was made between 'searching for meaning' and increased levels of depression at 18 months post-loss for participants characterised as reaching 'higher levels of sense-making' $\beta=.604, p<.001$. However, removal of data from two participants reporting making 'some' or 'a great deal' of sense rendered the effect insignificant $p=.418$. These results were explained in terms of the 'normative' character of loss experienced by the CLOC sample (due to participants being elderly). However variables relating to the context of death were

not included, despite their potential influence on whether and how one seeks meaning after loss (Coleman & Neimeyer, 2010).

In contrast to these findings, Boerner et al. (2005) found that participants who were 'chronically depressed' (high pre- and post-loss depression) were significantly more likely to search for meaning at 48 months post-loss than participants following any of the other bereavement patterns $t(87)=-2.86, p<.01$. These findings were explained in terms of the possibility that those who are chronically depressed may be more likely to ruminate about their situation (Nolen-Hoeksema, Parker, & Larson, 1994, cited in Boerner et al., 2005). However, the relatively small sample size at 48 months ($n=82$) meant that these results could be due to lack of statistical power.

Another study examining the effects of meaning-related (pre-loss predictor) variables on post-loss depression was that of Bonanno et al. (2002). In this study, 'resilient' (low pre- and post-loss depression) participants were significantly more accepting of death than 'common grievers' and 'chronic grievers' $F(4,80)=3.99, p<.01$. The 'resilient' group also had a significantly greater belief in a just world than 'common grievers' $F(4,80)=3.00, p<.05$. Whereas those categorised as 'chronically depressed' were associated with higher scores on the belief in the uncontrollability of negative events $F(4,80)=2.00, p<.10$. 'Resilient' individuals were therefore suggested as having protective worldviews, which mitigate against the effects of bereavement (Bonanno et al., 2002).

The disparate results provided by these studies suggest difficulties in how searching, and sense-making was conceptualised. In their study, Coleman and Neimeyer (2010) acknowledged the lack of construct validity for these two variables, thus limiting the

scope for broad conclusions to be made about the protective or contributory nature of these factors. These limitations raise questions regarding whether the exploration of this abstract and individual aspect of human experience may best be studied using qualitative methods (i.e. Interpretative Phenomenological Analysis).

Social Economic Status (SES)

Social economic status was the final protective/contributory factor relating to personal resources identified from the papers included in this review. Whilst no study specifically focused on the influence of SES on bereavement outcome, findings related to this factor were reported in two studies (Carr, 2004; Galatzer-Levy & Bonanno, 2012). Carr (2004) found that participants who had reported an interest in forming a romantic relationship and were dating at the time, were found to have significantly lower depressive symptoms at 18 months post-loss $p < .05$. However this effect ceased when SES was controlled for, thus suggesting that the lower depressive symptoms were attributable to reduced financial burden (Carr, 2004). Galatzer-Levy and Bonanno (2012) provide further support of factors relating to SES being influential in the development and/or continuation of depression post-loss; they found that financial stress predicted higher levels of post-loss depression even among groups who did not show high levels of depression throughout bereavement.

1.3.5 Quality and nature of the marital relationship

Two studies examined the effects of specific aspects of the marital relationship on post-loss depression in spousally bereaved older adults (Carr et al., 2000; Bonanno et al., 2002), once again yielding contrasting results. Using estimates of OLS regression Carr et al. (2000) examined whether warmth-closeness, conflict and

instrumental dependence affected depression in spousally bereaved older adults at six months post-loss. Whilst effects were seen on measures of anxiety and yearning, none of these dimensions of the marital relationship were related to post-loss depression scores (Carr et al., 2000). This finding was explained in terms of the importance of considering the unique pathways of 'passive depression' and 'active distress' following loss (Carr et al., 2000). A strength of this study was that utilisation of pre-loss reports of marital quality reduced the effects of positive/negative bias on this data.

Bonanno et al. (2002) operationalised 'qualities about the marriage' (measured by positive and negative evaluations), 'ambivalence about the spouse/marriage', 'interpersonal dependency' and 'dependency on the spouse' as pre-loss predictor variables of post-loss depression. Pairwise comparisons revealed that whilst the 'chronically-depressed' showed the highest levels of interpersonal dependency and dependency on the spouse compared with all other groups, 'chronic grievers' scored significantly higher on the same variables when compared to the 'resilient group' ($F(4, 80) = 3.30, p < 0.05$ and $F(4, 80) = 2.58, p < 0.05$ respectively). This finding suggested that those who are highly dependent on their spouse may be susceptible to higher levels of post-loss depression (Bonanno et al., 2002). Those who were categorised as 'chronically depressed' also had the least positive and most negative evaluations of their spouse, suggesting that when perceived negatively, quality of marriage contributed towards continued high levels of post-loss depression (for those with high pre-loss scores) (Bonanno et al., 2002). However, for participants in the 'depressed-improved' group, negative evaluations and ambivalence towards

their marriage appeared to contribute towards reduced depression post-loss (Bonanno et al., 2002).

The contrasting findings between these studies could be due to the different aspects of marriage examined in each study, which is suggestive of the complexity involved in measuring such a concept quantitatively. Another consideration is that Bonanno et al. (2002) predicted effects of marital quality at both six and 18 months post-loss, whereas in her study, Carr et al. (2000) did not utilise data beyond the six month point.

1.3.6 Demographic factor

The final potentially protective/contributory factor in depression following spousal loss in older adults was that of race. This was the only demographic factor, which was specifically studied in terms of its potential effect on bereavement outcomes.

In her study, Carr (2004) examined whether the effects of spousal loss were different for people dependent on their racial background. Estimates of OLS regression were used to examine the relationship between race (“Blacks” and “Whites” (Carr, 2004, p. 591)) and depressive symptoms at six months post-loss. The results showed participants did not differ in terms of depressive symptoms at baseline or six months. After addressing the small sample size (for those who identified themselves as black) as a potentially confounding factor, it was concluded that race was not a predictor of depressive symptoms. A limitation of this study is that it did not make clear whether “Blacks” referred to African Americans, or if it was used to describe non-white/Caucasian individuals, thus conclusions cannot be made regarding the influence of race on post-loss depression levels. This is supported by the findings

from the study carried out by Schulz et al. (2001), which showed race being the only covariate to yield a significant effect: African-Americans were found to have significantly lower levels of depression at both pre and post-loss, $p=0.2$.

1.3.7 Additional Critique

Whilst the benefits of using longitudinal design to examine the effects of spousal loss on bereavement outcomes are evident, a number of additional limitations prevented clear conclusions from being made.

The majority of papers included in this review use data from the CLOC study, therefore, the evidence relating specifically to depression in spousally bereaved older adults is reliant on one particular pool of data with participants recruited from one geographic area of the USA. This has clear implications on how far any of the findings can be related to all older adults i.e. it cannot account for differences in bereavement outcomes of those who live in different cultures and/or countries. Another issue was observed in terms of how different researchers extracted their samples from the overall CLOC sample. The number of participants sampled from each time point was not always consistent, for example, two studies examining data from the same time points – pre-loss and six months post-loss had a different number of participants (Reid Keene & Prokos, 2008; Pai & Carr, 2010). The reasons why studies included/excluded data was not always clear, thus raising questions regarding how well findings reflected the overall sample of the CLOC study.

An additional concern was the extent to which the studies can be generalised to *all* older widows and widowers. Whilst the average age of participants was stated as being 65 or older, eligibility into CLOC required only the husband to be 65 years or

older, therefore some of the data included may have been from female participants as young as 38 years old. Furthermore, the CLOC study underrepresents men and those of black and ethnic minorities. Selective attrition showed that adults who were older and particularly anxious were less likely to participate in the CLOC study; the potential implication of this is that overall findings were not reflective of those who might experience the most difficulty when losing a spouse.

Another methodological issue relates to the statistical analyses utilised in these studies. Regression and/or analyses of variance identified a number of multiple effects between variables, however causation of effects cannot be concluded from these analyses. Related to this was how studies varied in their decisions to include specific (potentially confounding) variables in their analyses; for example, some controlled for marital quality, whilst others did not. An implication of such issues lead to difficulty in extrapolating and synthesising the findings of these studies to draw clear conclusions relating to protective and/or contributory factors in post-loss depression. A final and important issue relates to the fundamental principles of conducting research. All of the studies included in this review tailored their hypotheses to fit previously obtained data, as opposed to identifying hypotheses and subsequently developing appropriate methodologies to test them. Whilst notwithstanding the practical and pragmatic benefits to approaching research in this way, it may also explain the variance in results despite using predominantly the same pool of participants.

1.4 Discussion

The discussion below outlines how far specific factors were identified in this review as protective, contributory (or undefinable) in depression following spousal loss in older adults. The findings and limitations are considered in relation to previous literature.

1.4.1 Protective factors

Two aspects of personality were considered moderately protective; high levels of extraversion and conscientiousness were associated with lower depression scores at six months. Extraversion was associated with a greater ability to organise social support, in addition to abilities in forming and maintaining positive relationships with others (Pai & Carr, 2010). This is supported by previous literature stating that among other features, extraversion is associated with individuals who have a tendency to be sociable and active (Eysenck, 1975). Described as associated with individuals who are organised, reliable, punctual and self-disciplined (Bratt, Stenström, & Rennemark 2015), conscientiousness was considered beneficial in coping with the practical challenges of losing a spouse (Pai & Carr, 2010).

Whilst contradictory findings regarding specific aspects of the caregiving situation prevents definitive conclusions relating to their protective/contributory nature, care giving in itself appeared to moderate depressive symptoms in three studies (Bonanno et al., 2002; Prokos & Reid Keene, 2005; Taylor et al., 2008). These findings reflect the continued debate regarding the complex relationship between caregiving and bereavement outcomes (Aneshensell, Botticello, & Yamamoto-Mitani, 2004; Boerner, Schulz, & Horowitz, 2004).

The finding that some specific contextual aspects of social support was protective in post-loss depression (Ha et al., 2011) was supported by previous literature indicating the importance of both perceived availability and quality of support in coping with acute stressors (Cohen and Willis, 1985). However, more recent studies have found no evidence of social support buffering against the negative effects of spousal loss in older adults (Stroebe, Zech, Stroebe, & Abakoumkin, 2005). As supported by previous literature (Schwartz & Sendor, 1999), self-reported helping behaviours, another aspect of social support, was also considered protective.

The protective nature of religious coping was identified in Carr and Sharp's study (2013). This was supported by previous studies indicating to an association between religious coping and improved bereavement outcomes, due to the perceived benefits of religious rituals, support of a religious community and/or belief that God will protect (Davidson, & Doka, 1999; Clarke, Hayslip, Edmundson, & Guarnaccia, 2003).

For participants following the 'depressed-improved' bereavement pattern, it was argued that their increased ambivalence and negative evaluations of marriage/spouse, protected them from post-loss depression (Bonanno et al., 2002). These findings have challenged previous assumptions that high ambivalence would be associated with 'chronic grievers', and that as such, for 'depressed-improved' individuals, spousal death was experienced as a release from a stressful marriage (Wolff & Wortman, 2005).

1.4.2 Contributory Factors

In support of previous studies evidencing the link between pre- and post-loss depression and/or grief responses (Lindermann, 1944; Norris & Murrell, 1990), three

studies in this review found pre-loss depression predictive of post-loss depression (Bonanno et al., 2002; Boerner et al., 2005; Galatzer-Levy & Bonanno, 2012). Participants who were 'chronically depressed' were found to have low levels of extraversion and high neuroticism. Linked to dispositional tendencies towards anxiety, depression, guilt, shyness, moodiness and emotionality (Eysenck, 1975), neuroticism has been associated with increased bereavement distress (Robinson & Marwit, 2006). Such tendencies may explain why 'chronically depressed' individuals also reported the least positive and most negative evaluations of their spouse/marriages, stronger beliefs in the uncontrollability of negative events and low instrumental support. As Wolff and Wortman (2005) suggest, it seems possible that for 'chronically depressed' individuals, the event of spousal loss exacerbates pre-existing enduring emotional difficulties.

Low levels of instrumental support from others were also contributory for those who were 'chronic grievers' (Bonanno et al., 2002). This finding could be considered in relation to previous arguments that those who are depressed and angry following bereavement may behave in a way that distances them from social support (Stroebe & Stroebe, 1987). In support of previous studies (Parkes & Weiss, 1983; Rando, 1988) Bonanno et al. (2002) also found that higher levels of interpersonal dependency and dependency on the spouse were associated with 'chronic grievers'. These individual differences could explain why some with low pre-loss depression appeared at a greater risk of experiencing depression, and other grief symptoms, following spousal loss. However, another (non-older adult) bereavement study has reported

contrasting findings relating to how interpersonal dependency is protective in certain circumstances (Denkcla, Mancini, Bornstein, & Bonanno, 2011).

The finding that belief in the existence of an afterlife but that reunification with a loved one is not possible contributed towards post-loss depression (Carr and Sharp, 2013), indicated the distressing nature of specific afterlife beliefs. In contrast to this, previous studies have eluded to the protective nature of afterlife beliefs in those who have been bereaved (Abrums, 2000; Benore & Park, 2004).

Galatzer-Levy and Bonanno (2012) associated financial stress with post-loss depression across all bereavement patterns. Reduced financial burden was also associated with improved depression at 18 months post-loss by Carr (2004). Whilst these findings support those previously reported (Stroebe & Stroebe, 1987; Sanders, 1988), Martikainen and Valkonen (1998) have also argued that SES alone is not predictive of significant differences in bereavement outcomes.

1.4.3 Undefinable Factors

A number of factors identified in this review could not be considered as protective or contributory. This was due to inconclusive and/or contradictory findings reported in relation to the effects of the same variable/s (factor/s) on depression as an outcome of spousal bereavement in older adults. These studies included those relating to death forewarning (Carr et al., 2001; Burton et al., 2006; Pai & Carr, 2010), specific aspects of caregiving (Schulz et al., 2001; Prokos & Reid Keene, 2005; Burton et al., 2006; Brown et al., 2008; Reid Keene & Prokos, 2008), searching and sense making (Bonanno et al., 2002; Coleman & Neimeyer, 2010;) and race (Schulz et al., 2001; Carr, 2004;).

In this review, the lack of conclusive findings regarding these particular variables are predominantly considered in terms of methodological and conceptual limitations. Empirical studies utilising variables that are lacking in construct validity are open to criticism (O’Leary-Kelly & Vokurka, 1998). This seems relevant to many of the studies included in this review, particularly with regard to a lack of consensus about how variables have been operationalised and measured. The additional likelihood of many of these variables being related to each other makes clear conclusions about the extent to which they are protective and/or contributory difficult. These limitations could be argued as being reflective of the challenge faced when attempting to explore the fundamentally individual experience of bereavement with a quantitative methodology.

1.4.4 Limitations of current review

Whilst the importance of examining depression as a bereavement outcome separate from others, including grief, complicated grief and yearning, is evident, one of the major limitations of this review is that its narrowed focus prevented exploring how depression is different and how it is related to other bereavement outcomes. Indeed where a number of studies included in this review reported no or limited effects on depression, the same studies found other aspects of the bereavement process as being influential. These findings support the argument for examining all aspects of the grief experience. A related limitation is that for studies to be eligible for this review they had to include a measure of depression as an outcome of bereavement; this resulted in no qualitative studies being reviewed. Thus the

individual nature of the bereavement experience and how this may relate to depression as an outcome was not explored.

Another limitation of this review was that by focusing on spousal loss, other types of relationships, including cohabiting partners, civil partnerships and/or same-sex marriages, were excluded. Focusing on the potentially protective and/or contributory factors in the development of bereavement-related depression for those in these types of relationships is likely to become increasingly relevant given societal differences between today's older adult cohort and that of 20 years ago.

1.4.5 Future research

Future research may wish to capture the experiences of the current older adult cohort. This would enable further studies to examine those who are in cohabiting and/or same-sex relationships in addition to comparing the differences between individuals who have experienced a number of long-term relationships, compared with those who have remained in the same relationship for a longer period of time. Future research may also explore data relating to the more intimate aspects of relationships and consider how issues relating to sex, affection and intimacy may impact on bereavement outcome following spousal loss in older adults.

1.4.6 Clinical Implications

The findings of this review suggest great variability between factors pertaining to be protective and/or contributory in post-loss depression. The clinical implications of such mixed findings indicate the value of retaining individual experience at the centre of any bereavement-related intervention.

A key consideration in bereavement intervention appears to be whether or not the person was depressed prior to their loss, as this may provide some indication to the likely pattern of bereavement. The length of time it may take for depressive symptoms to abate following loss is likely also to be affected by pre-loss mental health status. When working with individuals who are struggling to come to terms with their loss, it is also important to consider elements of their personality in terms of how well they are able to gather social support and deal with the practical challenges of loss, how dependent they were on their spouse and how they perceive the quality of their marriage. Additional consideration should be given to how well supported they feel by friends and family, and the context surrounding the loss i.e. did they care for their spouse, and was death sudden or expected.

1.5 Conclusions

This review has highlighted the complexity of attempting to understand bereavement-related-depression as separate from other aspects of the bereavement experience in older adults who have suffered the loss of a spouse. It has found that a number of different protecting or contributory factors may be influential in the presence of post-loss depression following spousal loss. However, it is possible that a lack of overall clarity between findings could reflect the intrinsically unique and individual experience of bereavement, which quantitative methodological study alone may struggle to capture.

1.6 References

- Abrums, M. (2000). Death and meaning in a storefront church, *Public Health*, 17(2), 132-142.
- American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders: DSM-5. *American Psychiatric Association*.
- Aneshensell, C. S., Botticello, A. L., & Yamamoto-Mitani, N. (2004) When Caregiving ends: The Course of Depressive Symptoms After Bereavement. *Journal of Health and Social Behaviour*, 45, 422-440.
- Benore, E. R., & Park, C. L. (2004). Death-Specific Religious Beliefs and Bereavement: Belief in an Afterlife ad Continued Attachment. *International Journal for the Psychology of Religion*, 14.1, 1-22.
- Boerner, K., Wortman, C. B., & Bonanno, G. (2005). Resilient or at Risk? A 4-Year Study of Older Adults Who Initially Showed High or Low Distress Following Conjugal Loss. *Journal of Gerontology*, 60B (2), 67-73
- Boerner, K., Schulz, R., & Horowitz, A. (2004). Positive Aspects of Caregiving and Adaptation to Bereavement, *Psychology and Aging*, 19(4), 668-675.
- Bonanno, G. A., & Kaltman, S. (2001). The varieties of grief experience. *Clinical Psychology Review*, 21, 705-734
- Bonanno, G. A., Wortman, C. B., Lehman, D. R., Tweed, R. G., Haring, M., Sonnega, J., Carr, D., & Nesse, R. M. (2002). Resilience to Loss and Chronic Grief: A Prospective Study from Preloss to 18-Months Postloss. *Journal of Personality and Social Psychology*, 83, 1150-1164.

- Bratt, S., Stenström, U., & Rennemark, M. (2015). The role of neuroticism and conscientiousness on mortality risk in older adults after child and spouse bereavement. *Aging and Mental Health*, 10.1080/13607863.2015.1031638
- Brown, S. L., Brown, R. M., House, J. S., & Smith, D. M. (2008). Coping with Spousal Loss: Potential Buffering Effects of Self-Reported Helping Behaviour. *Personality and Social Psychology Bulletin*, 34(6), 849-861.
- Burton, A. M., Haley, W. E., & Small, B. J. (2006). Bereavement after caregiving or unexpected death: Effects on elderly spouses. *Aging & Mental Health*, 10 (3), 319-326.
- Carr, D. (2004). Black/White Differences in Psychological Adjustment to Spousal Loss Among Older Adults. *Research on Aging*, 26, 591-622.
- Carr, D. (2004). The Desire to Date and Remarry Among Older Widows and Widowers. *Journal of Marriage and Family*, 66, 1051-1068.
- Carr, D., House, J. S., Wortman, C. Nesse, R., & Kessler, R. C. (2001). Psychological Adjustment to Sudden and Anticipated Spousal Loss Among Older Widowed Persons. *Journal of Gerontology: Social Sciences*, 56B (4), 237-248.
- Carr, S., & Sharp, S. (2013). Do Afterlife Beliefs Affect Psychological Adjustment to Late-Life Spousal Loss? *Journals of Gerontology, Series B: Psychological Sciences and Social Sciences*, 69 (1), 103-112.

- Carr, D., House, J. S., Kessler, R. C., Nesse, R. M., Sonnega, J., & Wortman, C. (2000). Marital Quality and Psychological Adjustment to Widowhood Among Older Adults: A Longitudinal Analysis. *Journal of Gerontology: Social Sciences*, 55B, 197-207.
- Clarke, S. M., Hayslip, B., Edmundson, R., & Guarnaccia, C. A. (2003). Religiosity, Afterlife Beliefs, and Bereavement Adjustment in Adulthood. *Journal of Religious Gerontology*, 14(2-3).
- Cohen, S., & Wills, T. A. (1985). Stress, social support, and the buffering hypothesis. *Psychological Bulletin*, 310-357.
- Cole, M. G., & Dendukuri, N. (2003). Risk Factors for Depression Among Elderly Community Subjects: A Systematic Review and Meta-Analysis. *American Journal of Psychiatry*, 160, 1147-1156.
- Coleman, R. A., & Neimeyer, R. A. (2010). Measuring Meaning: Searching for and Making Sense of Spousal Loss in Late-Life. *Death Studies*, 34 (9), 804-834.
- Costa, P. T., & McCrae, R. R. (1992). Normal personality assessment in clinical practice: The NEO Personality Inventory. *Psychological Assessment*, 4, 5-13.
- Davidson, J. D., & Doka, K. J. (1999). *Living with grief at work, at school, and at worship*. Washington, DC: Hospice Foundation of America.
- Denkcla, C. A., Mancini, A. D., Bornstein, R. F., & Bonanno, G. (2011). Adaptive and maladaptive dependency in bereavement: Distinguishing prolonged and resolved grief trajectories. *Personality and Individual Differences*, 51.8, 1012-1017.

- Emptage, N.P., Sturm, R., & Robinson, R.L. (2005). Depression and comorbid pain as predictors of disability, employment, insurance status, and health care costs. *Psychiatric Services, 56*(4), 468–74.
- Eysenck, H. J. (1975). *Manual of the Eysenck personality Questionnaire*. London: Hodder & Stoughton.
- Federal Interagency Forum on Aging Related Statistics. (2012). *Older Americans 2012: Key Indicators of Well-Being*. Retrieved from http://www.agingstats.gov/agingstatsdotnet/main_site/default.aspx
- Fiske, A., Loebach Wetherell., & Gatz, M. (2009). Depression in Older Adults. *Annual Review of Clinical Psychology, 5*, 363-389
- Galatzer-Levy, I. R., & Bonanno, G. A. (2012). Beyond normality in the study of bereavement: Heterogeneity in depression outcomes following loss in older adults. *Social Science and Medicine, 74*, 1987-1994.
- Gorman, M. (1999). Development and the rights of older people. In J. Randel., T. German., & D. Ewing (Eds), *The ageing and development report: poverty, independence and the world's older people* (pp.3-21). London, Earthscan Publications.
- Ha, J., & Ingersoll-Dayton, B. (2011). Moderators in the relationship between social contact and psychological distress among widowed adults. *Journal of Aging and Mental Health, 15* (3), 354-363.

- Hirschfield, R. M. A., Klerman, G. L., Gouch, H. G., Barrett, J., Korchin, S. J., & Chodoff, P. (1977) A Measure of Interpersonal Dependency. *Journal of Personality Assessment, 41*(6).
- Jozwiak, N., Preville, M., & Vasiliadis, H. M. (2013). Bereavement related depression in the older adult population – a distinct disorder? *Journal of Affective Disorders, 151*, 1083-1089.
- Kendler, K. S., Myers, J., & Zisook, S. (2008) Does Bereavement-Related Major Depression Differ From Major Depression Associated With Other Stressful Life Events? *The American Journal of Psychiatry, 165* (11), 1449-1455.
- Lindemann, E. (1944). Symptomatology and management of acute grief. *American Journal of Psychiatry, 101*, 141-148.
- Martikainen, P., & Valkonen, T. (1998) Do education and income buffer the effects of death of spouse on mortality? *Epidemiology, 9*(5), 530-540.
- Norris, F. H., & Murrell, S. A. (1990). Social support, life events and stress as modifiers of adjustment to bereavement by older adults. *Psychology and Aging, 5*(3), 429-436.
- Office for National Statistics. (2012). *General Lifestyle Survey Overview, 2010*. Retrieved from <http://www.ons.gov.uk/ons/rel/ghs/general-lifestyle-survey/2010/general-lifestyle-survey-overview-report-2010.pdf>.
- Office for National Statistics. (2013). *Measuring National Well-Being – Health 2013*. Retrieved from http://www.ons.gov.uk/ons/dcp171766_310300.pdf

Office for National Statistics. (2014). *Mid-2013 Population Estimates UK*. Retrieved from <http://www.ons.gov.uk/ons/rel/pop-estimate/population-estimates-for-uk--england-and-wales--scotland-and-northern-ireland/2013/stb---mid-2013-uk-population-estimates.html>

O'Leary-Kelly, S. W., & Vokurka, R. J. (1998). The empirical assessment of construct validity. *Journal of Operations Management*, 16(4), 387

Oxford Dictionary (2015a) Oxford Dictionaries Language Matters. Retrieved from <http://www.oxforddictionaries.com/definition/english/spouse>

Oxford Dictionary (2015b) Oxford Dictionaries Language Matters. Retrieved from <http://www.oxforddictionaries.com/definition/english/conjugal>

Pai, M., & Carr, D. (2010). Do Personality Traits Moderate the Effect of Late-Life Spousal Loss on Psychological Distress? *Journal of Health and Social Behaviour*, 51 (2), 183-199.

Parkes, C. M., Weiss, R. S. (1983). *Recovery from bereavement*. New York: Basic Books.

Prokos, A. H., Reid Keene, J. (2005). The Long-Term Effects of Spousal Care Giving on Survivors' Well-Being in Widowhood. *Social Science Quarterly*, 86, 664-682.

Radloff, L. S. (1977). The CES-D Scale A Self-Report Depression Scale for Research in the General Population. *Applied Psychological Measurement*, 1, 385-401.

- Rando, T. (1988). Anticipatory grief: The term is a misnomer but the phenomenon exists. *Journal of Palliative Care*, 4, 70-73.
- Reid Keene, J., & Prokos, A. H. (2008). Widowhood and the end of spousal caregiving: relief or wear and tear? *Aging and Society*, 4, 551-570.
- Robinson, T., & Marwit, S. J. (2006). An Investigation of the Relationship of Personality, Coping and Grief Intensity Among Bereaved Mothers. *Death Studies*, 30 (7).
- Sanders, C. (1988). Risk Factors in Bereavement Outcome. *Journal of Social Issues*, 44(3), 97-111.
- Schulz, R., Beach, S. R., Lind, B., Martire, L. M., Zdaniuk, B., Hirsch, C.,...Burton, L. (2001). Involvement in Caregiving And Adjustment to Death of a Spouse. *JAMA*, 285 (24).
- Schwartz, C. E., & Sendor, M. (1999). Helping others helps oneself: response shift effects in peer support. *Social Science and Medicine*, 48, 1563-1575.
- Stroebe, M., Schut, H., & Stroebe, W. (2007). Health outcomes of bereavement. *Lancet*. 370, 1960-1973.
- Stroebe, W., & Stroebe, M. S. (1987). *Bereavement and Health: The Psychological and Physical Consequences of Partner Loss*. Cambridge University Press.
- Stroebe, W., Zech, E., Stroebe, M., & Abakoumkin, G. (2005). Does Social Support Help In Bereavement? *Journal of Social and Clinical Psychology*, 24(7), 1030-1050.

- Spanier, G. (1976). Measuring Dyadic Adjustment: New Scales for Assessing the Quality of Marriage and Similar Dyads. *Journal of Marriage and Family*, 38(1).
- Taylor, D. H., Kuchibhatla, M., Østbye, T., Plassman, B. L., & Clipp, E. C. (2008). The effect of spousal caregiving and bereavement on depressive symptoms. *Aging & Mental Health*, 12(1), 100-107.
- Tooth, L., Wain, R., Bain, C., Purdie, D.M., & Dobson, A. (2004). Quality of Reporting of Observational Longitudinal Research, *American Journal of Epidemiology*, 161 (3).
- Wakefield, J. C., Schmitz, M. F., & Baer, J. (2011). Relation between duration and severity in bereavement-related depression, *Acta Psychiatrica Scandinavica*, 124(6), 487-494.
- Wilson, K., Mottram, P., & Sixsmith, A. (2007) Depressive symptoms in the very old living alone: prevalence, incidence and risk factors. *International Journal of Geriatric Psychiatry*, 22(4), 361-366.
- Wolff, K., & Wortman, C. (2005) Psychological consequences of spousal loss amongst older adults: Understanding the Diversity of Responses, in D. Carr., R. Ness & C.B. Wortman (Eds.), *Spousal Bereavement in Late Life*. New York: Springer Publishing Company.
- Zisook, S., Paulus, M., Shuchter, S. R., & Judd, J. (1997). The many faces of depression following spousal bereavement. *Journal of Affective Disorders*, 45(1-2), 85-95.
- Zisook, S., & Shuchter, S. R. (1991) Depression through the first year after the death of a spouse. *Am J Psychiatry*, 148, 1346-1352.

Zisook, S., Shuchter, S. R., Sledge, P. A., Paulus, M., & Judd, J. (1994). The spectrum of depressive phenomena after spousal bereavement. *Journal of Clinical Psychiatry*, 55, 29-36.

Chapter Two

Empirical Paper

‘Traversing the Unpredictable Terrain of COPD’: A Grounded Theory study of community nurses’ experiences of working with people who have COPD

Word Count: 7959 (excluding figures, tables, quotes and references)

Abstract: 150

Target Journal: Journal of Qualitative Health Research

2. Abstract

Despite estimates that Chronic Obstructive Pulmonary Disease (COPD) will be the third leading cause of death by 2030 (World Health Organisation, 2015) relatively little research has explored the perspectives of nurses caring for those affected. To explore this the current study interviewed nine community nurses working with patients with COPD. A Grounded Theory approach generated a model representing how participants coped in their roles. The core category 'Traversing the Unpredictable Terrain of COPD' showed how working with the reality of COPD required nurses to engage in the constant process of pulling towards and pushing away from death. Clinical implications indicate that all nurses be offered appropriate time for reflection and the opportunity to develop advanced communication skills. Future studies may explore gender, culture and race related issues influencing care, in addition to the experiences of other health-workers and those working with patients in the early stages of COPD.

Keywords: Grounded Theory; Chronic Obstructive Pulmonary Disease; Community Nurse; Experience; Coping

2.1 Introduction

This introduction presents a rationale for conducting research with community nurses working with people who have COPD; it will initially discuss COPD and nursing, followed by the impact of workplace stress on the profession. It will then examine palliative care and community-based palliative nursing.

2.1.1 COPD and COPD nursing

According to the Global Initiative of Chronic Obstructive Lung Disease (GOLD), COPD is:

“a common preventable and treatable disease characterised by persistent airflow limitation that is usually progressive and associated with an enhanced chronic inflammatory response in the airways and lung to noxious particles or gases” (GOLD, 2015, p.2).

Whilst preventable and treatable, COPD is not curable; it has high mortality rates that increase with age and co-morbidity of other associated illnesses such as cardiovascular disease (GOLD, 2015). COPD is mainly associated with the long-term effects of smoking; however, it can also be genetically influenced and can occur in non-smokers (GOLD, 2015). The COPD illness trajectory is best described as unpredictable (Spathis & Booth, 2008). Slow physical decline is marked by acute, sometimes fatal, exacerbations of dyspnoea (breathlessness). These are often followed by periods of limited improvement, though never returning to previous levels of health. In addition to promoting self-management strategies, providing pharmacological intervention and monitoring exacerbations, treatment often requires providing oxygen to assist patients' breathing.

The psychological impact of COPD for the patient is far-reaching; the constant presence of breathlessness can affect patients' views of themselves in society, causing feelings of isolation and helplessness (Harris, 2007). The suggestion that health care professionals need to be alert to whether a patient's anxiety is an indicator of the onset of dyspnoea also raises dilemmas about whether anxiety is

causing the dyspnoea or vice-versa (Harris, 2007). A further challenge faced by professionals caring for those with COPD is the complex prognostication associated with the disease, and the uncertainty relating to the transition from palliative care to end-of-life (EoL) status (Curtis, 2008). This ambiguity has been associated with poor communication regarding EoL issues between professionals, patients and families (Curtis, 2008). Poor communication has thus been attributed to the finding that those with COPD are more likely to die at hospital than to receive palliative-care services than patients with lung cancer (Gore, Brophy, & Greenstone, 2000).

Of the studies that have been conducted in COPD nursing, most are qualitative and focus on in-patient care and/or specific elements of the disease and/or treatment. These include the experiences of providing education to patients with COPD, how nurses manage malnutrition in patients with COPD, and nurses' experiences of acute exacerbation (Bailey, Colella & Mossey, 2004; Odencrants, Ehnfors, & Grobe, 2007; Zakrisson & Hagglund, 2010; Kvangarsnes, Torheim, Hole, & Öhlund, 2012). Such studies have identified particular qualities and skills perceived as relevant to nursing patients with COPD; these include using individual clinical judgment and intuition (Bailey et al., 2004; Odencrants et al., 2007), an ability to convey confidence (Zakrisson & Hagglund 2010; Kvangarsnes et al., 2012), and developing trusting relationships that were based on emotional reciprocity and respect for patients' emotional experiences (Odencrants et al., 2007; Kvangarsnes et al., 2012;). These findings help to provide an understanding of how patients benefit from appropriate nursing care. However, considering the personal and emotional impact of nursing this patient group may provide further insight into how this care can be given.

Other studies have focused specifically on issues relating to end of life (EoL) discussions with patients at the end-stages of their illness (Spence et al., 2009; Crawford, 2010;). Barriers to these conversations include the unpredictability of COPD and associated difficulty in balancing hope with truth (Spence et al., 2009; Crawford, 2010), in addition to communication difficulties with other health professionals and a general lack of knowledge about palliative care services (Spence et al., 2009). How nurses consciously manage their own emotions during these interactions appears contingent on the extent to which they become emotionally involved with their work (Crawford, 2010). These studies raise questions about how confident and skilled health professionals feel in their ability to discuss EoL issues with patients, in addition to how nurses strike the balance between emotional involvement and containment.

2.1.2 Nursing: An emotionally demanding occupation

In light of the emotional challenges faced by nurses working with COPD patients, it is important to consider the impact and consequences of workplace stress on their capacity to provide care. Occupational stress related to nursing has been the focus of considerable research due to the frequent exposure of nurses to emotionally challenging situations, often compounded by working under constantly changing organisational structures (Clegg, 2001). In studies that have sought to identify sources of stress within the context of nursing, working with death and dying, exposure to human suffering and death, emotional over-involvement and dealing with helplessly ill patients have all been identified (Dewe, 1987; Guppy & Gutteridge,

1991; Downey, Bengiamin, Huer, & Juhl, 1995; Kushnir, Rabin, & Azulai, 1997; Trifiletti, Di Bernardo, Falvo, & Capozza et al., 2014).

The impact of workplace stress has been linked to burnout, which is associated with absenteeism, intention to leave and actual turnover, in addition to reduced job satisfaction and reduced commitment to the role and/or organisation (Maslach, Schaufeli, & Leiter, 2001). The emotionally demanding nature of nursing has been associated with burnout; this is due to the requirement for individuals to regulate their own emotions whilst demonstrating sensitivity towards others (Zapf, Siefert, Schumutte, Mertini, & Holz, 2001). Controlling emotional expression during interactions with patients may conflict with nurses' own emotional needs and lead to the suppression of their own emotions, thus resulting in differences between feeling and behaviour (Smith, 1991). Applied to the context of nursing, burnout could be considered an indication of the nurses' increasing inability to control and manage their emotions when interacting with patients (Zapf et al., 2001).

The coping mechanisms adopted by nurses to manage workplace stress have been considered in qualitative and quantitative studies. Some mechanisms involve "dehumanisation" or the distancing from the distressing aspects of human suffering (Triviletti et al., 2014, p.769) and/or adopting a "work persona" that enables individuals to "switch off" (Mackintosh, 2007, p. 988.). Le Sergent and Haney (2005) used Lazarus and Folkmans' (1984) theory of cognitive appraisal to suggest that nurses become more reliant on 'emotion-focused' coping (i.e. avoidance, seeking social support) as their perceived lack of control makes 'problem-focused' coping less

advantageous. The 'restorative' aspect of reflection has also been suggested as enabling nurses to make sense of their stressful workplace environments within the safety of clinical supervision (Clegg, 2001). Whilst these studies provide insight into the impact of and coping mechanisms associated with workplace stress, there is a lack of research focusing on the experiences of nurses working specifically with patients who have COPD.

2.1.3 Palliative and End of Life care

Consideration of the issues encountered by nurses working in palliative care is necessary to further understand the experiences of those working with patients who have COPD (a palliative condition). According to the World Health Organisation (WHO), palliative care emphasises the importance of improving quality of life for patients and their families facing the problems associated with life-threatening illness; though encompassing EoL care, palliative care is recommended as being applicable early into the course of an illness (WHO, 2015).

Whilst providing a focus for a broad range of studies, much of the palliative care nursing research is based within hospice or care-home settings (Hodgson, Landsberg, & Lehning, 2006; Miller & Han, 2008; Pfister, Markett, Müller, & Grützner, 2013). Hospice nurses have reported lower levels of burnout and psychological distress when compared with nurses working in other specialities (Ablett & Jones, 2006). In addition, studies have found an increased sense of job satisfaction linked to working with dying patients and their families (Ablett & Jones, 2006). Ablett and Jones (2006) found that for hospice nurses working with patients with terminal cancer, talking with colleagues, using humour and maintaining work-life balance helped them to remain resilient. However, whilst this study promotes understanding of resilience in

palliative nurses, it does not indicate whether other factors, such as the duration of time participants have spent working in these settings, impacts upon resilience. The study also prompts questions about whether similar findings would be generated in a study based on care in an earlier stage of non-malignant yet life-limiting illness.

2.1.4 Community nursing and palliative care

The literature on community nursing in palliative care suggests that nurses in these roles face challenges as to how the work fits within the generalist role of district nursing and its impact on service delivery and patient care (Burt, Shipman, Addington-Hall & White, 2008). Dunne, Sullivan and Kernohan (2005) argue that the role of the district nurse is fundamental to palliative care in terms of coordinating services, providing symptom management and emotional support to patients and families. Together with the argument that patients prefer to die at home (Higginson & Sen-Gupta, 2000; National Council for Palliative Care, 2015), these findings warrant research in this area.

Tomison and McDowell's (2011) qualitative study explored the needs of palliative care community nurses working with people with both malignant and non-malignant long-term conditions. The study underlines service requirements from the perspective of the community nurse, including support with therapeutic relationships, coordination and clinical care, access to other services and collaborative working. However, the personal cost of working in such an emotionally challenging role is not explored. A further study, which focused specifically on the environmental experiences of community nursing, found that travelling long

distances between patients constrained nurses' ability to provide EoL care (Kaasalainen et al., 2014).

It is evident from the literature discussed above that the focus of existing research concentrates on the experiences of hospital/hospice based nurses working with patients who have COPD, with less attention being paid to the roles of district/community nurses working in palliative and EoL care. The nature of COPD is likely to present nurses with specific challenges which are different from those seen in other illnesses (Disler & Jones, 2010). However, despite the prevalence of the illness and the likelihood of the need for community care, there is a scarcity of research that focuses on community nurses' overall experience of working with patients who have COPD. Furthermore, little is known about how nurses working with this patient group cope with the emotionally demanding nature of their roles, and associated risk of stress-induced burnout. This oversight means that no existing research has sought to understand how community nurses working with patients who have COPD experience and manage their roles. Through the utilisation of Grounded Theory (GT), this research intends to generate a model of coping that will address this gap in the literature.

2.1.5 Research aims:

Research Objective: To explore how community nurses experience and manage working with patients who have COPD.

Research questions:

1. What helps community nurses to cope in their roles when working with patients who have COPD?

2. What hinders the coping processes of community nurses working with patients who have COPD?

2.2 Method

2.2.1 Design

The exploratory nature of this study and paucity of research in this area lent itself to a qualitative research methodology. In consideration of its ability to facilitate the shift from description of experience to an understanding of process (Strauss & Corbin, 1998; Corbin & Strauss, 2008), Grounded Theory (GT) was employed as the overarching method. In keeping with the researcher's epistemological position of social constructivism, a constructivist GT method was adopted. This enabled all data and analyses to be considered as constructions of both participant and researcher involved in a joint process of interpreting meanings and actions (Charmaz, 2006).

The data for this research was collected through semi-structured interviewing, enabling an in-depth enquiry of participants' experiences of working with COPD patients.

2.2.2 Participants

Participants were recruited from community based nursing teams and COPD teams working in the National Health Service (NHS). Nine participants volunteered to take part in the study. These included nurses from the specialist COPD team, palliative care team and general community teams (including Matrons). In order to be eligible to take part in the study, participants had to meet the following inclusion criteria:

- To have worked autonomously (post qualified) as a nurse for at least one year

- To have experience of working in the community with patients with a diagnosis of COPD at any stage of the illness
- To be English speaking

Participants were aged between 38 and 56 years old, and had between 2 and 30 years of working autonomously in post. Experiences of working with patients with COPD ranged between four and 'hundreds' and all except one participant worked full time (37.5 hours per week). All participants were white British.

2.2.3 Measures

An interview schedule was developed (see Appendix D) ensuring that:

- i) Questions explored the topic in that they were sufficiently general to cover a wide range of experiences and narrow enough to elicit participants' specific experiences.
- ii) Questions reflected a symbolic interactionist emphasis on learning about participants' views. This was underpinned by the assumption that participants can and do think about their own actions rather than acting automatically.

The interview schedule was used as a prompt during each interview. In acting as a guide to facilitate participants' discussion of important issues relevant to their experiences, it was not essential for questions to directly correspond with the questions included in the schedule (Barker, Pistrang, & Elliott 2002). The schedule was reviewed with a clinical psychologist working in physical health; amendments were made accordingly. In line with GT methods, analysis was carried out

concurrently with the interviews; the schedule was therefore reviewed continuously and altered according to what the data revealed (Charmaz, 2006).

2.2.4 Procedure

2.2.5 Recruitment

The researcher disseminated information about the study with service/team leads. This information was then cascaded to potential participants, who subsequently volunteered to participate. All potential participants were provided with written information sheets about the study, prior to interviews taking place (Appendix E). The process of theoretical sampling (see Analysis of Data) resulted in focusing recruitment on the Palliative Team towards the latter stages of data collection to elaborate on categories derived through preceding interviews.

2.2.6 Interview

Interviews were audio-recorded and conducted in a quiet meeting room at an agreed NHS location. In addition to providing informed consent (See Ethical Considerations), participants also completed a demographics questionnaire immediately prior to the interview (Appendix F). At the end of the interviews, participants were given opportunity to ask any questions and request copies of their transcript, and the final paper.

2.2.7 Ethical Considerations

This research was carried out in accordance with The British Psychological Society's Code of Ethics and Conduct (2009). Ethical approval for this study was given by Coventry University Ethics Board, and the relevant Research and Development departments (R&D) (see Appendix G).

All participants were required to complete *Consent to Participate* (Appendix H) forms prior to their interviews, this confirmed they had provided informed consent for their involvement. Participants were assured confidentially and that this would only be breached in exceptional circumstances, e.g. if the safety of themselves or others were at risk. All participants were made aware of their right to withdraw their data within a time period agreed by the relevant R&D departments. All participants were given at least two opportunities to ask questions about the study prior to being interviewed. At the end of each interview, participants were provided with a post-interview information sheet detailing who they should contact if they required subsequent support (see Appendix I).

2.2.8 Analysis of data

All interviews were transcribed verbatim, and analysed using GT procedures (Glaser & Strauss 1967; Strauss & Corbin 1998; Charmaz 2006):

- i) *Line-by-line coding* involved extracting and defining all relevant actions occurring in each line of the data (Charmaz, 2006). *Focussed coding* techniques enabled the most significant and/or frequently occurring line-by-line codes to be used to analyse larger sections of data (Charmaz, 2006). The process of *axial-coding* (Strauss & Corbin, 1998) enabled organisation of the data according to how categories and sub-categories appeared to be related (see Appendix J for a coded transcript excerpt).
- ii) Considered as the crucial link between data collection, theoretical analysis and conclusion (Charmaz, 2006), *memo-writing* was undertaken in order for thoughts and ideas about the emerging data to be considered

at each part of the process. The *constant comparative method* was utilised, requiring the constant analytic distinction and comparison of data against that of subsequent interviews (Glaser & Strauss, 1967). This allowed codes and/or categories to remain *active*, which enabled sensitivity towards processes rather than just description (Charmaz, 2006). *Memo-writing* was critical in elevating codes to *conceptual categories*, which formed the basis of the emerging analytic model (see Appendix K and L).

- iii) *Theoretical sampling* involved gathering subsequent data based on significant categories in order to develop the emerging model. Data collection ceased when *theoretical sufficiency* had been reached i.e. when all categories had been developed to a sufficient extent that was possible to draw some conclusions from their relationships (Dey, 1999).

2.2.9 Issues of quality

In order to address quality issues associated with the inherently subjective nature of qualitative research, specific consideration was given to ensuring that this study had “commitment and rigour”, and “transparency and coherence”, in accordance with Yardley’s (2000, p.219) quality framework.

Commitment and rigour was achieved by adopting the following procedures, as proposed by Barker and Pistrang (2005):

- Analysis by a separate researcher who was independent of the research project, enabled an overall *consensus* to be gained relating to the analysis and

interpretation of data. A number of codes were discussed and alternative focused codes developed.

- Attempts were made to carry out *respondent validation* checks with the research participants, in order for them to comment on and provide insights into the emerging theory as it progressed.

The researcher's social constructivist epistemological position views knowledge as being constructed through the purposes, perspectives and activities of those who create it (Seidel & Kelle, 1995). This required her to be aware of her own reflexivity throughout the research process, thereby maintaining *transparency*. The process of "bracketing" enabled the researcher to identify her pre-existing knowledge and preconceptions relating to the field of study in order to understand how these may influence analysis (Ahern, 1999, p. 407). A reflective journal was kept throughout the research process enabling the researcher to identify if/when analysis was being influenced by personal motivation, judgment and external system pressures.

2.3 Results

A model of coping processes emerged from analysis of the data (Figures 1 and 2). The model illustrates how the core category of 'Traversing the Unpredictable Terrain of COPD' embraces seven conceptual categories representing the multiple processes participants engage in. These processes reflect the constant movement between life and death. Against the backdrop of 'Working with Time', the star illustrates how 'Managing the Reality of COPD' involves accompanying patients to the edge of death, only for them to be pushed back towards life again. The process of 'Death: Travelling to The Precipice' illustrates movement from the known (life) to the unknown (death).

Positioned close to the centre of the model is the conceptual category of 'Trusting Relationships', the development of which is crucial to the nurses' perception of how closely they can accompany patients on their journeys. The process of 'Giving' demonstrates how nurses give a part of themselves to these relationships and also illustrates their desire to act in order to improve the journey towards death. Accompanying these patients on their journeys is not unconditional; nurses' investment is made by continuously 'Evaluating (their) Own Resilience'. The nurses' ability to engage in these processes is contingent on them 'Negotiating the (multitude of) Limits' imposed on them. These limits are conceptualised in terms of systemic and individualised factors.

The fluidity between categories is illustrated by the dotted lines in the model. The following explanation describes how the conceptual categories interact, in addition to demonstrating how each one stands alone.

Traversing the
Unpredictable
Terrain of COPD

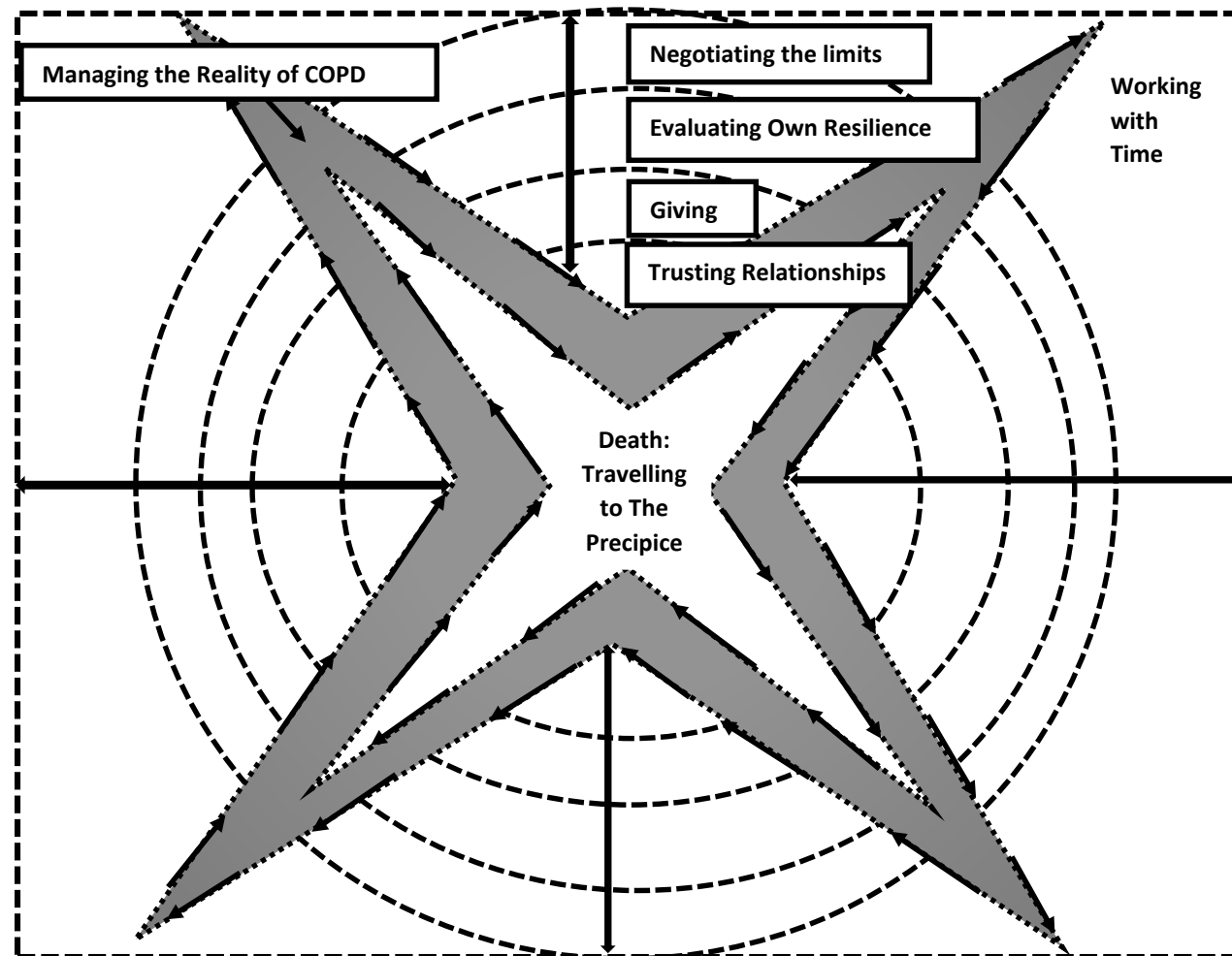


Figure 1: Model

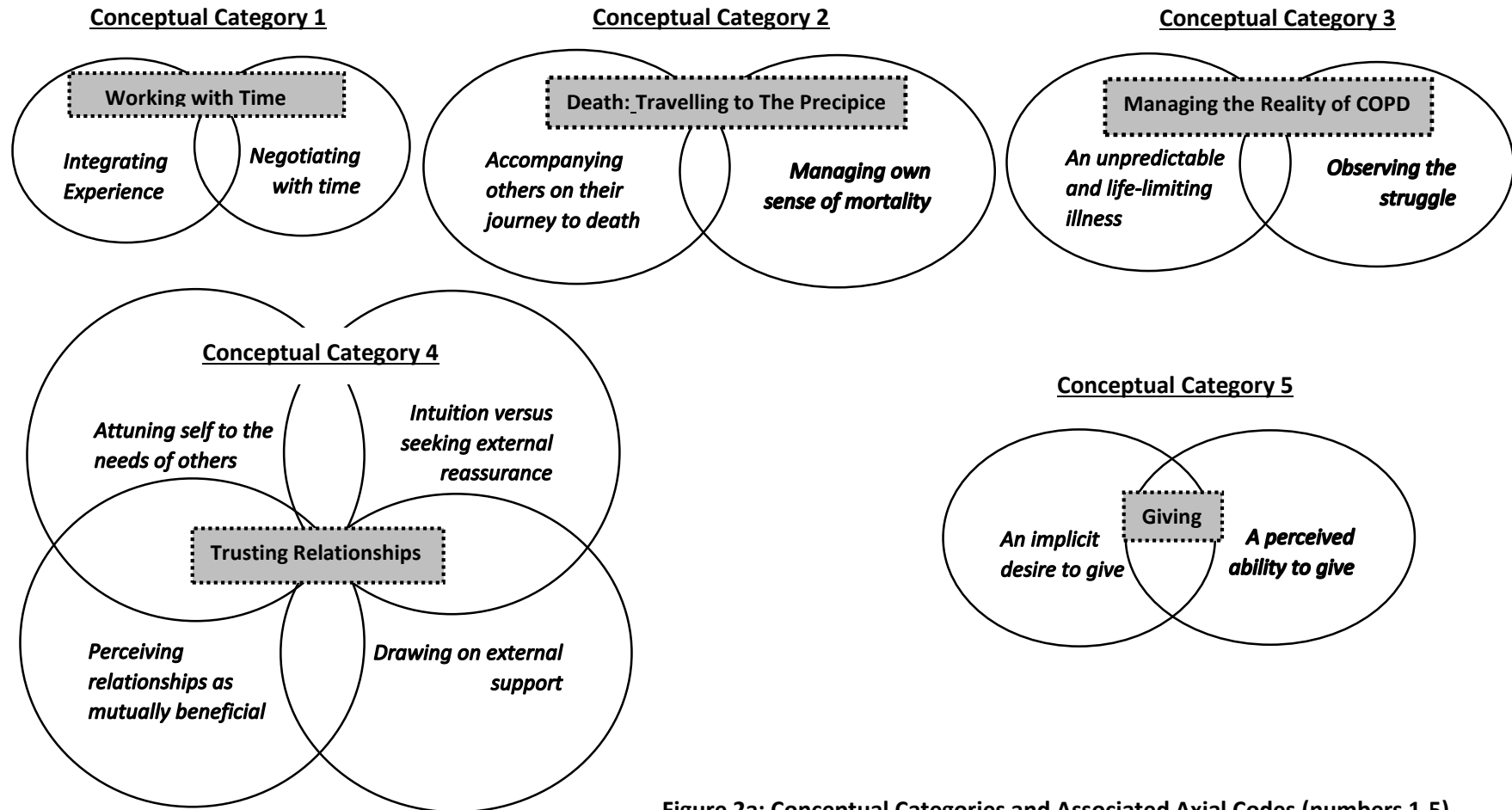
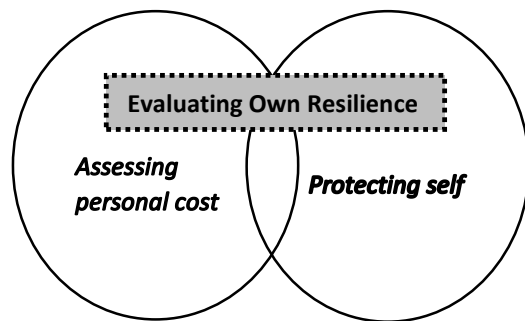


Figure 2a: Conceptual Categories and Associated Axial Codes (numbers 1-5)

Conceptual Category 6



Conceptual Category 7

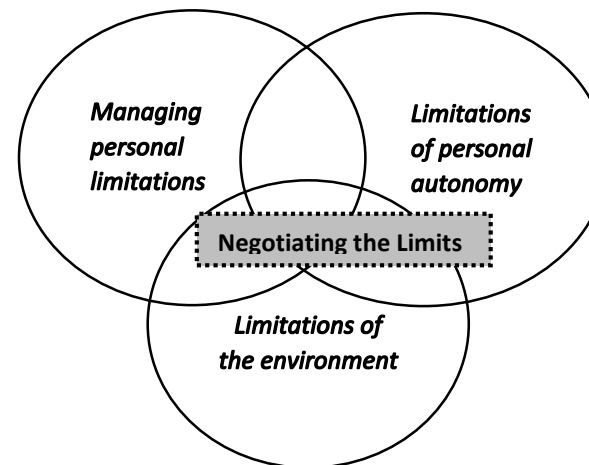


Figure 2b: Conceptual Categories and Associated Axial Codes (numbers 6-7)

2.3.1 Conceptual category 1: Working with Time

In demonstrating how participants are constantly working with the overarching restrictions of time, this category links closely to all others in the model, and comprises of two axial codes: *Negotiating with time* and *Integrating experience*.

Negotiating with time

Linking with 'Negotiating the Limits', participants found ways of coping with the time pressures imposed on them by COPD. Empowering patients to improve their quality of life was a crucial way of doing this. As Dawn states:

'The people coming through now [early stages], it's just so important that they realise that it's a massive opportunity to keep things good and to keep themselves well' (L476-478)

Integrating experience

Many participants spoke about the advantages of having more experience of working with patients with COPD. Nurses who had been qualified for longer attributed their confidence and competence to their years of experience, as stated by Tina:

'I feel quite competent and confident in what I do, erm COPD, the treatment, it's about a differential diagnosis. I'm 10 years down the line, you know' (L34-35)

Whereas, those who had less experience spoke of a greater need to seek the advice, reassurance and support from more experienced colleagues:

'but at the moment I do believe their [other professionals] knowledge is obviously better than mine because I'm only two years in now, I've spent one year in hospital and one in the community; I'm new to the community' (Tracy L196-198)

Demonstrating the link with 'Trusting Relationships', participants used their experiences to develop relationships with patients and/or relatives within the time parameters imposed on them by COPD. Time to develop 'Trusting Relationships' varied across roles, as Jackie and Amy state:

'it was easier working with those you'd built up a good rapport with, that you'd had from day one sort of thing you know. And because you'd built up that special relationship with them' (Jackie L118-119)

'Yeah because I think it's more intense isn't it, I think it's more, it's a very quick relationship but it's a more intense relationship' (Amy L511-513)

2.3.2 Conceptual Category 2: Death: Travelling to The Precipice

The undeniable presence of death for patients with COPD punctuated participants' accounts of their experience. Comprising of two axial codes: *Accompanying others on their journey to death*, and *Managing own mortality*, this category demonstrated how the process of actively moving towards and pulling away from death reflected the way COPD pushes patients and participants to and from The Precipice.

Accompanying others on their journey to death

Participants described needing to prepare patients and their relatives for the journey towards death; this included establishing when and how to approach the subject of

death. This decision was connected to nurses' attunement to patients' readiness for this conversation, linking to 'Trusting Relationships':

'And you have to work out, wait a moment, can they handle that? You're quite conscious that you're in their home and you're gonna leave, so you wanna know that when you leave, you're not leaving somebody who starts "now I'm dying!"' (Freda L126-130)

The journey towards death required participants to be actively engaged in assisting patients to look over the side of The Precipice or standing beside those who chose not to look:

'most patients at that stage realise that time is short and will say "do you know, I've had enough" so they're kind of expecting those talks...so we do it together' (Amy L160-162)

Managing their own sense of mortality

Travelling towards death with patients appeared to increase participants' awareness of their own mortality, thus their own constructions of death were often related to being prepared:

'Every day you wake up is a blessing, it is because you don't know what's waiting for you around the corner, and again it's trying to get those wish lists – your bucket list if you will' (Sandra L148-150)

Participants' death narratives seemed connected to both personal and professional experiences and were also highly related to their perception of the COPD journey:

'I can honestly say in all of those deaths that I've seen, they're all different, but it all has the same end....there's never a good death really. And that goes with COPD patients as well, you know, unfortunately' (Freda L524-527)

2.3.3 Conceptual Category 3: Managing the Reality of COPD

'Managing the Reality of COPD' represents how participants manage the challenges of COPD. These challenges are strongly implicated in 'Death: Travelling to The Precipice', and comprises of two axial codes, *An unpredictable and life-limiting illness* and *Observing the struggle*:

An unpredictable and life-limiting illness

The unpredictable nature of COPD was spoken about by all participants, some of whom also compared it to the relatively '*straight forward*' prognosis associated with cancer (Dawn, L74). Related to this was participants' need for clarity over patients' EoL choices; some spoke of taking responsibility for having these conversations with patients, despite sometimes questioning whether they were best placed to do so. Amy describes how other professionals who have cared for patients, sometimes for years, might be better placed for such conversations:

'they're in a better position to talk about advanced care planning....we can sometimes go in and only know a patient for a few days, or maybe a few weeks, it could be months but we don't know' (Amy L148-154)

Observing the struggle

Participants' descriptions of their experiences of COPD often reflected observing patients' battles with breathlessness. Watching a patient struggle for breath was described by most as scary; this was particularly relevant when remembering initial experiences of the illness. The link with the conceptual category 'Giving' is evident in how participants were driven by the desire to help these patients in any way possible, as Jackie explains:

'you want to breathe for them, you want to take away that effort, you can see the effort that... they're struggling' (L342-343)

2.3.4 Conceptual Category 4: Trusting Relationships

'Trusting Relationships' represents the function of these relationships as enabling (or hindering) nurses to travel with patients to The Precipice. Positioned on the innermost circle, 'Trusting Relationships' reflects the interaction between this and the other four categories positioned within the outer circles. Relationships were constructed as being with patients, families, professionals and also themselves. This category comprised of four axial codes: *Attuning self to the needs of others*, *Intuition versus external reassurance*, *Relationships as mutually beneficial* and *Drawing upon external support*.

Attuning self to the needs of others:

An awareness and ability to align themselves with the needs of those around them was central to participants' development of 'Trusting Relationships'. This complex

process, which appeared linked to experience ('Working with Time'), involved balancing the needs of the patient alongside those of relatives:

'..each family are different, and everyone handles things in a different way and it's about trying to go with their needs' (Freda L154-155)

Some nurses articulated being attuned to when and how to support patients, even at the most challenging times:

'there's a lot to be said about the touch, the holding of the hand and that reassurance and I think because you've built up that relationship with that patient, you know what works for them' (Jackie L134-135)

Linking with 'Death: Travelling to the Precipice' was the participants' understanding of patients' and/or relatives' readiness to discuss death, and that this overrode external pressures regarding the need for these conversations to be held:

'When they're ready to talk, they'll talk' (Jackie L324)

Attunement was also conceptualised as participants' awareness of patient/relatives' need for honesty; adopting an honest/direct approach therefore enabled them to form intrinsically trusting relationships:

'I'm not going to lie to them, because that would then erm denigrate the trusting relationship that I have got with them to help them manage, so it's based on truth' (Sandra L113-114)

Intuition versus seeking external reassurance

Linking closely to 'Working with Time' and 'Negotiating the Limits', participants' awareness, confidence and associated ability to trust their own intuition varied according to role and experience. Some felt more able to use their intuition:

'I'm one of those that's a bit more, I go by my gut feeling, I do go by what I feel is right' (Dawn, L540-540)

Whereas those with less experience tended to seek direction from more experienced others:

'because like I say, I don't always know what to do.... And it's about being honest...and saying "do you know what, I need someone a bit more senior"'
(Tracy L561-564)

Perceiving relationships as mutually beneficial

Relationships were also seen by participants as mutually beneficial. Sometimes patients and/or relatives allowed them to feel either 'like a friend' or 'part of the family', as Freda shows when talking about meeting a patient in the street:

'and I'd go past her [patient] and I'd stop, you know, it's, it's almost like a friendship' (L195-196)

Drawing upon external support

All participants articulated the importance of being able to draw upon the external support of colleagues and other professionals. Most participants spoke of being part of a close team, and that those team relationships helped them cope with the

emotional distress elicited by their roles, especially where formal clinical support was lacking:

'We used to have clinical supervision and stuff like that... no. I don't have, there's no time, there literally isn't the time' (Freda L241-244)

'We support each other, I think that's it....we work quite close and we do help each other out and have a good sister at the front of it as well' (Freda L573-575)

2.3.5 Conceptual category 5: Giving

'Giving' represents participants' fundamental desire to help others through the role of nursing. It is closely related to 'Trusting Relationships', 'Evaluating own Resilience' and 'Negotiating the Limits', and is comprised of two axial codes: *An implicit desire to give* and *A perceived ability to give*.

An implicit desire to give

An implicit desire to give was articulated by all participants, at many different levels, including the extent to which they invested into developing trusting relationships. Feeling able to 'do their best' provided participants with a sense of self-validation:

'To try and fulfil them [wishes] as much as you can...that's one of the last things you can try and give a patient' (Tracy L485-486)

Implicit giving was also seen in participants' desire to contain the emotions of others – providing a calming approach despite their own distress:

‘...a lot of the time it is me parking my emotional response and getting into my professional mode and just trying to do my best to calm them down’ (Sandra L409-411)

A perceived ability to give

Linking with ‘Death: Travelling to The Precipice’, the perception of creating the right circumstances that enabled a ‘good death’ helped participants traverse the difficult terrain leading up to The Precipice. Good death was constructed in terms of patients being prepared, pain-free, comfortable and where they wanted to be:

‘I think being able to make somebody’s journey – giving them good quality of life, um making them pain free, comfortable contented as possible has got to be a good death’ (Shirley L126-127)

In connecting ‘Giving’ with ‘Working with Time’, participants also articulated the desire to give patients improved and/or sustained quality of life through empowering them to be aware of life as well as death:

‘that’s right [smoking has caused damage] but you know, “we [patient, relative & nurse] can be doing an awful lot more to make his quality of life better”’ (Jackie speaking with a patient’s relative L279-281)

2.3.6 Conceptual category 6: Evaluating Own Resilience

Linking closely to ‘Giving’ and ‘Negotiating the Limits’, ‘Evaluating Own Resilience’ represented participants’ attempts to maintain congruence between how much they wanted to give, and how much they could give to their roles. This category is comprised of two axial codes: *Assessing personal cost* and *Protecting the self*.

Assessing personal cost

Assessing personal cost was expressed most explicitly in the extent to which participants felt able to engage in 'Trusting Relationships' with patients. For more experienced nurses, becoming emotionally involved in these relationships was an essential part of their role; 'feeling' the pain associated with losing patients was used as a way of knowing that they 'were still there':

'I know I'm still there because I can still cry with my patients and they choke me up and I can see patients and you, so I'm not emotionally dead or emotionally burnt out' (Tina L338-339)

However, some participants also expressed that becoming over-invested in every relationship was not possible, as Dawn states:

'I don't feel like this [emotional] about absolutely everybody, you know, you couldn't survive' (L306-307)

Protecting the self

Participants all articulated a need to protect themselves from some of the distress elicited by their roles. This was evident in how participants dealt with the ending of relationships imposed by death; the unpredictability of COPD meant that finding closure was sometimes difficult:

'with the COPD patients it's slightly different because sometimes they'll end their days in hospital..... So you don't always get that same kind of closure with COPD' (Freda L210-212)

For those who could attend funerals, many, like Tina chose not to:

'I never go to funerals cos that's my way of coping' (L149-150)

For those whose roles did not allow them to attend funerals, 'moving on' was the most efficient way of coping with the loss, as stated by Freda:

'you move on to the next one' (L239)

Talking was a key coping strategy for all participants. Those who were more experienced utilised reflective skills, which protected them from burning out:

'and then after the event, I would sit back and reflect and I would write down, we used to reflect in our own little circles of matrons, we used to support each other' (Jackie L155-159)

Participants who had not received formal training to develop reflective skills spoke of talking to their colleagues and friends/relatives as a way of restoring themselves following distressing cases/situations:

'I usually have a hissy fit, I go upstairs [to team] and have a tantrum, and someone will say 'well you could do this' or 'you could do that' Oh I never thought of that' (Freda L568-569)

Demonstrating the link with 'Giving', receiving external validation from patients and/or relatives (in the form of verbal appreciation) was used by participants to assess whether the extent of what they wanted to give was good enough. Establishing this congruence was conceptualised as implicitly protective:

'And that you couldn't personally do anymore....and the family do thank you for that' (Tracy L587-588)

2.3.7 Conceptual category 7: Negotiating the limits

Located on the outer circle of the model, 'Negotiating the Limits' interacts with all other conceptual categories. It represents how participants negotiated the multitude of limitations imposed on them by COPD, and is comprised of three axial codes: *Managing personal limitations*, *Limitations of patient autonomy* and *Limitations of environment*.

Managing personal limitations

Closely related to 'Assessing own Resilience', participants articulated an awareness of when to accept their own limits had been met. These were often construed in relation to how they saw themselves as 'being human', i.e. vulnerable:

'you're always preparing yourself, because you are human and you do have feelings, you can't switch them feelings off....in the community they [patients] stay, forever, you know, until they die' (Tracy L405-407)

Conveying their own boundaries and limitations to patients, relatives and other professionals was an important part of managing their own limits, as shown by Amy:

'Yeah so I always make sure they [patients] know who I am, what I'm doing, what I'm there for' (L536)

The limitations of patient autonomy

All participants expressed ways of accepting that patients should be permitted to exercise their own autonomy over care decisions, regardless of how unwise others perceived these decisions to be:

'you have to just learn to accept that adults can make their choices, sometimes they're not good choices and they're not the choices you would have liked for them; however, it's their choice, and their right...' (Tracy L302-304)

This was also evident in the way that nurses worked with patients who seem unwilling or unable to accept/follow treatment recommendations, particularly in relation to patients who continued to smoke:

'I just think well probably that's up to them isn't it? they obviously think well they've got it [COPD] so stopping smoking isn't going to make any difference because they've already got it' (Lucy L169-171)

The limitations of the environment

Relating to 'Trusting Relationships' and 'Giving', the limitations imposed on participants by the home environment was construed as being mostly beneficial. Being treated at home enabled patients to exert more control over their own environment, which required participants to adhere to different sets of contextual boundaries. Working within these boundaries helped nurses to facilitate the development of 'Trusting Relationships'. This positively impacted on their ability to provide patient care:

'When I nurse somebody, I wanted to be able to deal with all their problems before I walked away.....if I go into somebody's home and I go in and they're poorly and exacerbation and [having] a bad day, I'm able to spend as much

time as I need with that individual because at that time they're my priority'
(Tracy L226-233)

Most participants experienced pressure imposed by the wider system relating to the need to prevent hospital admissions; however, they negotiated these boundaries by remaining focused on the patient:

'although I'm there for admission avoidance.... although it's part of my job, what's more important to me is that they have a decent quality of life and that, you know, what's it, that they have a life' (Tina L484-486)

2.4 Discussion

2.4.1 Summary of findings

The aims of this study were to explore how community nurses experience working with COPD patients, and to understand how they cope in their roles. The model produced reflects how working with the reality of COPD involves nurses engaging in a constant process, alongside their patients, of pulling towards and pushing away from the inevitability of death. This is set against a backdrop of 'Working with Time'. The extent to which nurses are able to accompany their patients on this journey is contingent on a number of different processes. Nurses integrate their implicit and explicit desire to give to the development of the trusting relationships with patients, relatives, professionals and themselves. Such relationships are fundamental to providing the perceived level of care required. The extent to which nurses invest into these relationships is contingent on a constant evaluation of personal resilience, driven by the need to protect themselves. Coping mechanisms are employed to

establish congruity between *desire* and *actual* ability to give, through self and external validation. These are primarily facilitated by perceived experience in role and access to external, formal and informal, support. In order to ascertain their own levels of personal resilience and capacity, nurses are actively engaged in a process of negotiating the limits imposed upon them by both contextual and personal factors.

As the core category 'Traversing the Unpredictable Terrain of COPD' suggests, the uncertainty of COPD prognosis was central to many of the participants' experiences. Previous studies suggest poor communication between health professionals, patients and families was attributed to the unpredictable nature of COPD; as a result, patients were less likely to receive appropriate EoL care (Curtis, 2008; Spathis & Booth, 2008). Whilst participants in the current study did concede that patients did not always have a good death, emphasis was placed on the nurses' roles allowing them opportunity to ensure that patients' EoL wishes were carried out to the best of their abilities. Indeed, as the conceptual category 'Giving' demonstrates, creating the right circumstances to enable a good death was incredibly important to those interviewed. Developing 'Trusting Relationships' with patients, families and health professionals played a crucial role in enabling this.

In their review, Spathis and Booth (2008) highlighted the importance of preparing patients with advanced COPD for death as this helped to provide an increased sense of control over and associated ability to plan for the event of death. Crawford (2010) found that the uncertain illness trajectory of COPD made balancing hope with truth difficult, thus hindering respiratory nurses' attempts to discuss EoL issues openly with these patients. These findings were supported by Spence et al. (2009) who found

that health professionals expressed concern that patients with COPD would feel as though they were being 'given up on' if the subject of EoL/palliative care was raised. The pertinence of discussing EoL issues in the current study was evident in participants' willingness to have these conversations, despite the potential barriers. Being honest and direct with patients about their prognosis, although difficult was integral to how participants developed crucially trusting relationships with their patients. Addressing the subject of death meant that participants could then focus on empowering patients to achieve the best quality of life possible, within the contextual and personal limitations imposed on them.

As the conceptual category of 'Trusting Relationships' demonstrates, participants in the current study aspired to emotionally align themselves to the needs of those around them. When achieved, this process of attunement appeared to facilitate their ability to provide the right care, at the right time, according to individual (holistic) patient's needs. Building trust, in addition to developing emotional reciprocity, was discussed as important to intensive care nurses working with patients experiencing acute COPD exacerbation (Kvangarsnes et al., 2012). Developing emotional reciprocity was construed as enabling nurses to create a sense of safety as a way of reducing the anxiety and panic associated with acute exacerbation (Kvangarsnes et al., 2012). Another dimension of 'Trusting Relationships' identified in the current study related to the importance of developing these with other professionals, especially due to their roles as community nurses. This finding was supported by Tomison and McDowell (2011) who posited 'collaborative working' as a key service requirement identified by community nurses.

Previous literature has identified the use of intuition to guide clinical practice in working with patients who have COPD (Bailey et al., 2004; Odencrants et al., 2007). In their study, Bailey et al. (2004) suggested that judgments based on clinical intuition were vulnerable to being overlooked as a result of nurses using a shared COPD-illness template. This template reflected potentially unchallenged and inappropriate beliefs about patients' illness-related behaviours (i.e. attributing anxiety as the cause of patient distress, as opposed to it being a sign of distress). These findings contrasted with those of the current study, which identified how participants construed increased role-based experience as facilitating the ability to rely on intuitively-based clinical judgment, as opposed to seeking external reassurance. This was consistent with the argument that experienced 'expert' nurses instantly apprehend and compare clinical situations with those encountered previously, thus enabling them to act without the "conscious rational calculation" required of those less familiar to the role (Benner, Tanner, & Chesla, 2009, p. 208.). Such argument offers insight into why participants with fewer clinical encounters of COPD found drawing upon the support of others, and seeking external reassurance, a more integral part of their own experience. It also helps to explain how time and experience influenced the extent to which nurses were able to attune themselves to the needs of those around them.

The requirement of nurses to be able to regulate their own emotions whilst demonstrating sensitivity towards their patients has also been identified in previous literature (Zapf, 2001). Crawford (2010) found that the ability to contain emotions improved with nurses' experience in that recognising both their own emotions and those of others prevented them from becoming overwhelmed during interactions

with patients. Other findings have suggested the importance of nurses becoming emotionally involved in patients' emotional lives as this enables them to respond to patients and families in a sensitive and meaningful way (Benner et al., 2009). The findings of the current study supported this view in that experienced nurses were more able to 'feel' their emotions and use them to facilitate the care being provided to patients and/or relatives. For these nurses, this played an important part in knowing that they still cared about their patients, an aspect of experience, which for all participants, was construed as a fundamental requirement of their roles.

Whilst role-based experience appeared facilitative of participants' ability to establish the balance between involvement and containment, other related factors also appeared influential in this process. Corresponding to the findings of Ablett and Jones (2006) exploring the experiences of hospice nurses, all participants in the current study found that talking with colleagues, other professionals and friends and/or family helped them to cope with the distressing nature of their work. The desire and ability to be able to reflect upon clinical experiences was also considered a prominent aspect of the coping process, in that it enabled participants to evaluate their contribution towards clinical situations. This helped participants to establish congruence between the *desired* and *actual* level of care they could provide. Those with more specialist roles associated with increased nursing experience, such as the community matrons, were provided with a greater opportunity for reflection compared with those who had less experience, for example, clinical supervision and reflective practice. For the purposes of clarity, the term 'clinical supervision' refers to supervision between nurses, and 'reflective practice' refers to the opportunity for nurses to reflect upon their experiences with clinical psychologists. Whilst the

emotional component of reflection has been relatively neglected in the literature (Asselin, Schwartz-Barcott, & Osterman, 2012), studies have shown that reflecting on the use of empathy in relation to existing knowledge and experience is integral to nursing care (Gustafsson & Fagerberg, 2004). It is argued that the integration of knowledge and clinical experience can develop through clinical supervision where reflection may occur (Maggs & Biley, 2000). Furthermore, self-reflection can prompt nurses to consider their own achievements and how to use these to inform and teach others (Gustafsson & Fagerberg, 2004). Such arguments help to explain how the successful integration of often distressing clinical experiences, relating to working with people who have COPD, was contingent on role-based experience, thus also contributing towards the development of clinical intuition. This suggests that greater role-based experience facilitated participants' ability to immerse themselves more fully into the emotional lives of their patients (and families), thus feeling better equipped to manage the resulting emotional costs.

2.4.2 Strengths and limitations

This study addresses a previously neglected area in the literature by providing a valuable and rich explanation of how community nurses working with people with COPD, experience and cope in their roles. Although the study only investigated the social processes and experiences of community nurses, participants had varying levels of experience, which allowed a more comprehensive model to be created. This study gave a voice to a number of nurses (including those with fewer years of experience) who otherwise may not have been given the opportunity to express their views about working with this patient group in this setting.

Utilisation of GT methodology required meticulous and systematic analysis of the data, thus resulting in a model which is fully grounded in the experiences of the participants with whom it was produced. The dynamic nature of the model and fluidity between categories demonstrates the complexities of both the illness trajectory, and the parallel processes the participants engage in when working with patients with COPD. Elucidating these processes is beneficial in drawing attention to important implications regarding how nurses are supported to provide desired levels of care.

Whilst the GT model that emerged from the data conceptualises the processes participants engaged in when working with patients who have COPD, caution must be taken not to overgeneralise its findings. In keeping with social constructivism, this study does not assume that the saturation of categories was possible, thus aiming for and achieving 'theoretical sufficiency' (Dey, 1999). This must be considered in relation to how gaining other perspectives i.e. from community nurses working in different teams/ different NHS trusts/ geographic locations, may have altered the model that was produced. Related to this was the lack of representation of nurses from Black and Ethnic Minority (BME) groups, in addition to male nurses; this raises questions regarding how gender-related, race and cultural issues may influence experience and therefore provide a different perspective from that presented in this study. Furthermore, participants involved in this study were 'self-selecting', therefore consideration must be given to the extent to which the perspectives of those who chose not take part may have also produced different findings.

Whilst broadening the inclusion criteria to include nurses working with COPD at any stage of the illness, those who volunteered worked predominantly with patients at the later stages of their illness. Furthermore, participants tended to direct the focus of their experience towards issues relating to death, thus prompting theoretical sampling from a team of palliative care nurses. An additional consideration concerns how all except one participant worked fulltime, which meant conclusions could not be drawn in relation to the extent to which exposure to the workplace may have impacted experience and coping. The model presented in this paper is therefore reflective of experiences and coping processes of nurses working with those at the severe stage of illness, which means it should not be used to explain the same processes for those working with those at the earlier stages of COPD.

2.4.3 Clinical implications

It was apparent that those nurses who were afforded greater opportunity to reflect were those most able to invest in the fundamentally important relationships associated with their roles. This emphasises the importance of ensuring that all community nurses receive clinical supervision and reflective practice. Mcvey (2010), reports how nurses attending reflective practice groups, facilitated by clinical psychologists, benefitted in how they were able to compare their experiences with those in similar roles and also discuss emotional and distressful issues. Schwartz Rounds (Point of Care Foundation, 2015), which are meetings designed to encourage staff from all disciplines to reflect on the emotional experience of their work, have also been found to increase skills in empathy and openness to expressing thoughts, questions and feelings. However despite the evidence, in addition to guidance

provided by The Care Quality Commission (CQC) (2013) stressing that all registered professionals should receive adequate clinical supervision, the findings of this study reflect inequity of provision in this regard. It thus seems prudent to conduct service evaluations in order to determine the discrepancies between clinical supervision and reflective practice offered, and the opportunities taken up. As a consequence, organisational and personal barriers to receiving these types of supervision can then be identified and addressed.

In highlighting the complexity of addressing EoL issues with patients who have COPD, this study suggests the potential benefits of nurses receiving training in advanced communication skills. Previous literature has identified the advantages of this training for those nursing patients with cancer and heart disease (Wilkinson, Perry, Blanchard, & Linsell, 2008; Morris & Corbett, 2011). Through employing cognitive, behavioural and affective components, the training incorporates experiential learning in order to address individual nurses' clinical communication difficulties. The aim is to increase confidence and enhance the skills involved in responding to patients and effectively managing "difficult communication situations" (Wilkinson, Perry, Blanchard, & Linsell, 2008, pg. 366). Additionally, the Sage and Thyme programme was designed by the University Hospital of South Manchester NHS Foundation Trust (UHSM) to train all grades of staff how to respond and listen to patients and carers. This course facilitates the learning of effective communication skills that encourage raising EoL conversations with patients, and is stated as particularly suitable for those who have experience of advance care planning, i.e. community matrons (Sage & Thyme, 2015). Offering such training to community nurses working with patients with COPD would provide them with opportunity to

consider, in a safe and structured environment, how to effectively manage the frequent and difficult EoL conversations with patients and families of those affected by this illness.

2.4.4 Future research

Future research may include exploring the specific differences between hospital and community nurses, caring for those who have COPD, thus establishing the extent to which the coping processes identified in this study are more or less contingent on the environment. It would also be of value to learn about the experiences of nurses involved in the care of patients at the early stages of disease. However, these perspectives are more likely to be gained from a larger number of COPD specialist nurses, as opposed to district/matron nursing teams. As previously mentioned, one of the limitations of this study is in its underrepresentation of men and those from BME. The exploration of whether gender-related, cultural and race issues influence experience would provide a more complete understanding of how nurses manage in their roles. Additional experiences for further research include those of other health professionals (i.e. doctors, occupational therapists, physiotherapists) and non-qualified staff (i.e. support-workers and healthcare assistants) who work with patients with COPD.

2.4.5 Conclusion

A Grounded Theory approach was used to generate a model that reflects how community nurses experience and manage working with patients who have COPD. The core category of 'Traversing the Unpredictable Terrain of COPD' represents how working with the reality of COPD requires nurses to engage, alongside their patients,

in the constant process, of pulling towards and pushing away from the inevitability of death. Several interacting conceptual categories demonstrated how nurses engaged in facilitative and/or inhibitory processes. This represented the extent they were able to invest in providing the desired level of patient care. The findings suggest that all nurses working with this patient group would benefit from receiving appropriate time to reflect on clinical experiences and opportunity to develop advanced communication skills. Clinical psychology has a role in promoting the development of these areas as is evidenced by the Schwartz Rounds and Sage and Thyme programmes. Future research should consider the influence of gender, culture and race related issues on caring for patients with COPD. Exploring the experiences of those working specifically with patients in the early stages of the illness, as well as gaining perspectives of other health workers working with patients with COPD, would provide further insight into this field of study.

2.5 References

- Ablett, J. R., Jones, R. S. P. (2006). Resilience and well-being in palliative care staff: A qualitative study of hospice nurses' experience of work. *Psycho-Oncology* 16, 733-740.
- Ahern, K. J. (1999). Ten tips for reflexive bracketing. *Qualitative health research*, 9(3), 407-411.
- Asselin, M. E., Schwartz-Barcott, D., & Osterman, P. A. (2012). Exploring reflection as a process embedded in experienced nurses' practice: a qualitative study. *Journal of Advanced Nursing*, 69(4), 905–914.
- Bailey, P., Colella, T., & Mossey, S. (2004). COPD-intuition or template: nurses' stories of acute exacerbations of chronic obstructive pulmonary disease, *Journal of Clinical Nursing*, 13, 756-764.
- Barker, C., Pistrang, N., & Elliot R. (Eds) (2002) *Research Methods in Clinical Psychology: An Introduction for Students and Practitioners*, (2nd Eds), John Riley and Sons.
- Barker, C., Pistrang, N. (2005). Quality Criteria Under Methodological Pluralism: Implications for Conducting and Evaluating Research. *American Journal of Community Psychology*, 35, (3-4), 201-212.
- Benner, P. E., Tanner C, A., & Chesla, C. A. (Eds.). (2009) *Expertise in Nursing Practice*. New York: Springer Publishing Company.
- Burt, J., Shipman, C., Addington-Hall, J., & White, P. (2008). Nursing the dying within a generalist caseload: a focus group study of district nurses. *International Journal of Nursing Studies*, 45, 1470-1478.

- Charmaz, K, (2006). *Constructing Grounded Theory: A practical guide through qualitative analysis*. Sage Publications.
- Care Quality Commission (CQC) (2013). *Supporting information and guidance: Supporting effective clinical supervision*. Care Quality Commission.
- Clegg, A. (2001). Occupational Stress in nursing: a review of the literature. *Journal of Nursing Management*, 9, 101-106.
- Corbin, J., & Strauss, A. (Eds.). (2008). *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory* (3rd Ed.). Thousand Oaks, CA. Sage Publications.
- Crawford, A. (2010) Respiratory practitioners' experience of end-of-life discussions in COPD. *British Journal of Nursing*, 19, 18.
- Curtis J, (2008) Palliative and end of life care for patients with severe COPD. *European Respiratory Review Journal*, 32 (3), 796-803.
- Dewe, P. J. (1987) Identifying the Causes of Nurses Stress: A New Zealand Survey. *Work and Stress*, 1, 15-24.
- Dey, I. (1999). *Grounding grounded theory*. San Diego: Academic Press.
- Disler, R. & Jones, A. (2010). District nurse interaction in engaging with end-stage chronic obstructive pulmonary disease patients: a mixed methods study. *Journal of Nursing and Healthcare of Chronic Illness*, 2: 302–312.
doi: 10.1111/j.1752- 9824.2010.01071.x
- Downey, V., Bengiamin, M., Heuer, L., & Juhl, N. (1995). Dying babies and associated stress in NICU nurses. *Neonatal Network*, 14(1), 41-6.
- Dunne, K., Sullivan, K., & Kernohan, G. (2005). Palliative care for patients with cancer: district nurses' experiences. *Journal of Advanced Nursing*, 50(4), 372-80.

- Glaser, B. G., & Strauss, A. L. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Chicago: Aldine Publishing Company.
- Global Initiative for Chronic Obstructive Lung Disease (GOLD) (2015). *Global Strategy for the Diagnosis, Management and Prevention of COPD*, Retrieved April 21 from: <http://www.goldcopd.org/>.
- Gore, J.M., Brophy, C. J., & Greenstone, M. A. (2000). How do we care for patients with end stage chronic obstructive pulmonary disease (COPD)? A comparison of palliative care and quality of life in COPD and lung cancer. *Thorax*, 55, 1000–1006.
- Guppy, A., Gutteridge, T. (1991). Job satisfaction and occupational stress in UK general hospital nursing staff. *Work and Stress*, 5(4), 315-323.
- Gustafsson, C., & Fagerberg, I. (2004) Reflection, the way to professional development? *Journal of Clinical Nursing*, 13(3), 271–280.
- Harris, S. (2007) COPD and Coping with Breathlessness At Home: A review of the literature, *British Journal of Community Nursing*, Volume 12, no 9, p 411-5.
- Higginson, I. J., & Sen-Gupta, G. J. (2000). Place of care in advanced cancer: a qualitative systematic literature review of patient preferences. *Journal of Palliative Medicine*, 3(3), 287-300.
- Hodgson, N., Landsberg, L., Lehning, A., & Kleban, M. (2006). Palliative Care Services in Pennsylvania Nursing Homes. *Journal of Palliative Medicine*, 9.5, 1054-1058.

- Kaasalainen, S., Brazil, K., Williams, A., Wilson, D., Willison, K., Marshall, D...Phillips, C. (2014). Nurses' experiences providing palliative care to individuals living in rural communities, aspects of the physical rural setting. *Rural and Remote Health, 14* (6), 2728.
- Kushnir, T., Rabin, S., & Azulai, S. (1997). A descriptive study of stress management in a group of pediatric oncology nurses. *Cancer Nursing, 20* (6), 414-21.
- Kvangarsnes, M., Torheim, H., Hole, T., & Öhlund, L. (2012). Intensive care unit nurses' perceptions of patient participation in the acute phase of chronic obstructive pulmonary disease exacerbation: An interview study. *Journal of Advanced Nursing, 69.2*, 425-434.
- Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer.
- Le Sergeant, C, M., & Haney, C, J. (2005). Rural hospital nurse's stressors and coping strategies: A survey. *International Journal of Nursing Studies, 42*, 315–324.
- Mackintosh, C. (2007). Protecting the self: A descriptive qualitative exploration of how registered nurses cope with working in surgical areas. *International Journal of Nursing Studies, 44*, 982-990.
- Maggs, C., & Biley, A. (2000) Reflections on the role of the nursing development facilitator in clinical supervision and reflective practice. *International Journal of Nursing Practice, 6*, 192–195.
- Maslach, C., Schaufeli, W. B., Leiter, M. P. (2001). Job Burnout. *Annual Review Psychology, 52*, 397-422.
- Mcvey, J. (2010). Assessing the value of facilitated reflective practice groups. *Cancer Nursing Practice, 11*, 8, 32-37

- Miller, S. C., Han, B. (2008). End-of-life care in U.S. nursing Homes: Nursing homes with special programs and trained staff for hospice or palliative/end-of-life care. *Journal of Palliative Medicine*, 11(6), 866-877.
- Morris, J., & Corbett, A. (2011). Communication skills training in end-of-life care. *Nursing Times*, 107 (47), 16-17.
- National Council for Palliative Care. (2015). Commissioning End of Life Care Page, Act Early to Avoid A&E, Retrieved on April 8, 2015 from <http://www.ncpc.org.uk/sites/default/files/AandE>
- Odenrants, S., Ehnfors, M., & Grobe, S. J. (2007). Living with chronic obstructive pulmonary disease (COPD): Part II. RN's experience of nursing care for patients with COPD and impaired nutritional status. *Scandinavian Journal of Caring Science*, 21, 51-63.
- Pfister, D., Markett, S., Müller, M., Müller, S., & Grützner, F. (2013) German nursing home professionals' knowledge and specific self-efficacy related to palliative care. *Journal of Palliative Medicine*, 16.7, 794-798.
- Sage & Thyme. (2015). Retrieved on July 5, 2015 from <http://www.sageandthymetraining.org.uk/>
- Seidel, J., & Kelle, U. (1995) Different functions of coding in the analysis of textual data. In: U, Kelle (Ed.). *Computer-aided qualitative data analysis: theory, methods and practice*. London: Sage.
- Smith, P. (1991). The nursing process: raising the profile of emotional care in nurse training. *Journal of Advanced Nursing*, 6, 74-81.
- Spasis, A., & Booth, S. (2008). End of Life Care in Chronic Obstructive Pulmonary Disease: in search of good death. *International Journal of COPD*, 3(1), 11-29.

- Spence, A., Hasson, F., Waldron, M., Kernohan, W. G., McLaughlin, D., Watson, B...Marley, A. M. (2009). Professionals delivering palliative care: a qualitative study. *Palliative Medicine*; 23, 126–131.
- Strauss, A. L., & Corbin, J. (1990) *Basics of Qualitative Research: Grounded Theory Procedures and Techniques*, Sage Publications.
- Strauss, A. L., & Corbin, J. (1998) *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*. Sage Publications.
- The British Psychological Society. (2009). *Code of Ethics and Conduct*. The British Psychological Society.
- The Point of Care Foundation. (2015). Schwartz Rounds. Retrieved on July 5 from: <http://www.pointofcarefoundation.org.uk/schwartz-rounds/>
- Tomison, G., McDowell, J. R. S. (2011). Nurses' needs in delivering palliative care for long-term conditions. *British Journal of Nursing*, 16, 6.
- Trifiletti, E., Di Bernardo, G., Falvo, R., & Capozza, D. (2014). Patients are not fully human: a nurse's coping response to stress. *Journal of Applied Social Psychology* DOI: 10.1111/jasp.12267
- Yardley, L. (2000). Dilemmas in Qualitative Research. *Psychology & Health*, 15 (2), 215-228.
- World Health Organisation (2015) World Health Organisation, Chronic Respiratory Diseases, Retrieved April 21, 2015 from <http://www.who.int/respiratory/copd/en/>
- World Health Organisation (2015) WHO definition of palliative care, World Health Organisation Programme page, Retrieved April 8, 2015, from <http://www.who.int/cancer/palliative/definition/en/>

- Wilkinson, S., Linsell L., Perry, R., & Blanchard, K. (2008) Communication skills training for nurses working with patients with heart disease. *British Journal of Cardiac Nursing*, 3 (10). <http://dx.doi.org/10.12968/bjca.2008.3.10.31224>
- Wilkinson, S., Perry, R., Blanchard, K., & Linsell, L. (2008) Effectiveness of a three-day communications skills course with cancer/palliative care patients: a randomised controlled trial. *Palliative Medicine*, 22, 365. DOI: 10.1177/0269216308090770
- Zakrisson, A., & Hagglund, D. (2010). The asthma/COPD nurses' experience of educating patients with chronic obstructive pulmonary disease in primary healthcare. *Scandinavian Journal of Caring Science*, 24, 147-155.
- Zapf, D., Siefert, C., Schumutte, B., Mertini, H., Holz, M. (2001) Emotion Work and Job Stressors and their Effect on Burnout. *Psychology and Health*, 16, 527-545.

Chapter Three

Reflective Paper

Reflections on speaking with community nurses who work with people who have COPD

Word Count: 2883 (excluding references)

3.1 Introduction

My thesis included a grounded theory study exploring the experiences and coping processes of nurses who work with patients who have Chronic Obstructive Pulmonary Disease (COPD). This paper aims to explore a number of prominent reflections that were made throughout this research journey. I will first discuss reflections made in relation to some of the concepts and categories that emerged from my data. I will then reflect on aspects of the research process, specifically in relation to the utilisation of Grounded Theory.

3.2 Resonating experiences: working with death and dying

The conceptual category at the centre of my model was 'Death: Travelling to the Precipice', which represented the processes involved in the journey participants took with their patients in helping them to confront or avoid death. Whilst I was aware that death was likely to be a fairly prominent feature of this research from the outset, due to COPD being a palliative condition, I wanted to remain open to exploring experiences of working with patients who have COPD across all stages of the illness. However, as interviews progressed, I became increasingly aware of participants sharing more about their experiences of working with people at the end stages than those who had been more recently diagnosed. The data was drawing me towards exploring issues relating to death and dying, which encouraged me to seek more information about it from my participants. This prompted me to revisit some of my earlier reflections about the motivations driving me to conduct research in this area. From the outset, I was aware that the initial seed from which this piece of research has grown reflected my personal interest and motivation to understand more about

how other professionals work with those who are dying. I knew that this interest was driven partially through recent personal experience of loss, which had brought me a lot closer to thinking about the meaning and purpose of life, and the potential consequences of death for those left behind. I believe that the pain suffered in relation to my own experiences, and the fear associated with incurring future loss was hugely influential in directing me towards exploring the experiences of those working with death. Maintaining an awareness of these influences was integral to my analysis; it was important to know that the data was taking me towards death, as opposed to me directing it there based on my own personal motivations.

As the data unfolded and codes were raised to categories, I considered why 'Death: Travelling to the Precipice' seemed to have such personal resonance. I thought about my need to confront death, especially in terms of how my own experiences of loss had pulled me sharply away from the pleasures of life and living, and pushed me straight towards my own 'precipice'. At that time, I was forced to consider the uncontrollable and unavoidable presence of death and loss. Whilst this was a particularly sad and painful time for both my husband and myself, I remember feeling incredibly struck by the compassion shown towards us by medical professionals - particularly nurses, involved in our care. Beneath the medical jargon and task-orientated discussion, there was an unspoken understanding of the emotional pain we were feeling. I felt genuinely cared for by the nurses. This tacit connection enabled them to accompany me on a part of a journey that I was not even aware I was taking; they stood beside me, as I faced the physical and emotional aspects of my loss. Even at that time I felt curious as to how these nurses were able to provide

such warmth and kindness when their roles appeared to involve working with people who were experiencing such sadness.

Whilst listening to participants' experiences, the notion of them confronting death and accompanying others on their journeys towards death became increasingly explicit. I was struck by how important it was for participants to initiate end of life conversations with their patients, irrespective of how difficult this was for them. I reflected on their sensitivity towards this aspect of their work, especially in terms of them gauging when and how to approach this subject with each patient and family. These nurses are brave; they are facing a challenge, which many of us prefer to avoid. Not only are they discussing death with those who are dying, but they are doing it within the context of an incredibly unpredictable illness. There is never a straight forward response when a patient with COPD asks how long they have left to live.

These experiences encouraged me to broaden my own understandings of why some people are able to confront death, and the potential benefits of doing this. After all, surely avoiding death is the most effective way of being able to focus on living? In consideration of these matters, I was drawn towards some of the writings of Irvin Yalom (2008), and found the quote below particularly enlightening, especially in relation to some of the narratives offered by those interviewed:

"The way to value life, the way to feel compassion for others, the way to love anything with greatest depth is to be aware that these experiences are destined to be lost." (Yalom, 2008, pg 147)

The suggestion that having an awareness of our own temporality actually enhances our capacity to love and care for others felt relevant to the experiences of

participants interviewed in my study. ‘Switching off’ from the emotional lives of their patients and families was not a strategy employed by any of those interviewed; they all confronted the very real, emotionally challenging issue of death on a daily basis. An awareness of the temporality of life was not lost by them – as was described by Sandra:

“Every day you wake up is a blessing, it is because you don’t know what’s waiting for you around the corner..” (L148-149)

In these respects, perhaps it could be argued that a constant awareness of death and the impermanence of life contributed towards the care and compassion participants articulated about the patients they worked with. The same concept also helped me to consider more fully my own drive to confront the subject of death (through undertaking this research topic). By facing my own death anxiety, and allowing myself to think more openly about matters of an existential nature, was I gaining a greater and more fulfilling experience of the fundamental relationships upon which my very existence is centred?

Yalom (2008, pg 119) suggests, humans are “hardwired” to be connected with each other; living is thus centred on interpersonal connectedness. In stark contrast, death is associated with complete separateness – from others and also the world (Yalom, 2008). As my model emerged, the crucial roles of the relationships that participants have with their patients (and families) became more apparent. In one of my research meetings, a member of the team suggested that the emerging category ‘Trusting Relationships’ appeared to be ‘where the love lived’. I felt this comment accurately reflected the experience of many of my participants. I also considered its resonance

with Yalom's (2008) suggestion about human connectedness, especially with regard to the close link between 'Trusting Relationships' and 'Death – Travelling to The Precipice'. Though at odds with my preconceived views of life and death being opposing constructs, the data was showing me that for these participants, relationships (life) could not be considered without death. For them, being connected with their patients was contingent upon addressing the separateness of death. Equally so, addressing this separateness could not be done without the development of rich and meaningful relationships, despite how vulnerable this made participants to experiencing loss.

The notion of connectivity was demonstrated by how participants aspired to emotionally align themselves with the needs of others – being attuned to their patients facilitated trust and understanding. Noticing this prompted me to consider the complexities of achieving such attunement. At this point it was impossible to refrain from drawing parallels between my own role as trainee clinical psychologist and those in the nursing profession. For me, the heart of my work also lies in the relationships I am able to develop with those I work with – clients, colleagues and other professionals. Indeed, the importance of the therapeutic alliance in "all helping relationships", as posited by Hovarth (2001, pg 366) requires me to consider in-depth the processes at play when working clinically with others. In my role, I am afforded opportunity to formally and informally reflect upon these relationships, either through peer or clinical supervision. As recent literature suggests, clinical supervision is an essential part of the role of trainee and qualified clinical psychologists (Fleming & Steen, 2012); I have therefore never considered it optional and/or a luxury. For me, such practice is an essential to my understanding of myself in relation to others; it

helps me attune myself with the needs of those who I work with, whilst also allowing me to identify barriers to developing attuned relationships with some individuals. Ultimately, this facilitates my ability to provide appropriate, safe and effective interventions. It also helps to keep me safe.

Recent literature suggests that clinical supervision and reflective practice are becoming more common place within the nursing field (Bush, 2005); however my study highlighted a clear inequity of the provision of this between those community nurses participating in my study. All participants expressed how talking about their clinical experiences with others helped them to cope with some of the emotional distress of their roles; however, not all of them were given opportunities to do this in a formalised or structured way. I considered this in terms of how it reflected a fundamental difference between medical and psychological models. As a trainee clinical psychologist gaining experience of working in the field of clinical health psychology, I have found myself constantly asking where the body stops and the mind begins, and vice versa. I draw the same conclusion every time – there is no clear distinction; we are embodied. It was therefore difficult to imagine that some nurses, who are working so closely with the physical and emotional experiences of others, are not always receiving adequate support to understand and cope with these clinical experiences. One of the hopes I have from carrying out this piece of research is that it will draw attention to this deficit and at least plants the seed for consideration to be given to change in this respect.

3.2.1 Resonating Experiences: the reality of COPD

The reading I undertook whilst developing my research proposal had provided me with some knowledge of COPD but it was only through interviewing my participants that I became aware of the true suffering experienced by those who are afflicted by this illness. Hearing about the real experiences of those who are so actively engaged in helping COPD patients put me in touch with the necessity and validity of carrying out a piece of research in this area.

Prior to undertaking the interviews, I had considered my own preconceptions relating to the topic of COPD. One specific issue that I felt sure would be a prominent feature of participants' accounts was smoking, and the potential impact this may have had on their thoughts and feelings about patient care. As data collection progressed I noticed that this was not the case; whilst the subject of smoking was present in many interviews, it was not a prominent feature, and certainly did not appear to affect participants' views as to how patients should be treated. I considered these findings in relation to my own experiences of smoking, and felt drawn towards the fact that, until very recently, a very close relative of mine had been a heavy smoker of cigars throughout most of his adult life and that this was having a serious impact on his health. Shortly after carrying out my first interview, I remember sitting with him and telling him about COPD. I realised that as much as many of the nurses who took part in my research articulated, I too felt fearful that such a close member of my own family could potentially be the victim of an illness like COPD. I became aware of how over the years I had accepted this relative's choice to smoke; in fact, where I can't abide the smell of cigarette smoke, the wafting aroma of a Hamlet cigar reminds me

only of the warmth of him. On reflection I realised that just like those being interviewed, I felt frustrated by this person's choice to smoke but this made no difference to how I felt about the quality of the medical care and attention he required. Knowing this relative's history and the context of his smoking helped me to understand why it was something he continued to do despite the obviously negative impact on his health. In a similar way to those interviewed, I had found a way of accepting this person's choice.

3.3 Grappling with Grounded Theory

During the early stages of this project, I found myself moving towards conducting my research with a group of community nurses, whose experiences of caring for patients with COPD had not been explored before. It seemed clear to me that the research would be qualitative, I was less certain about which methodology would be the most appropriate to answer the emerging research questions. After much deliberation, a decision was made to utilise the methods of Grounded Theory (GT). I felt that unlike other methodologies (i.e. Interpretive Phenomenological Analysis – IPA), GT would enable me to explore more than a description of experience. As Cresswell (2008) suggests, GT is particularly useful when other theories about a phenomenon or social process do not exist. In facilitating an understanding of processes I would be able to establish *how* these nurses coped in their roles. However, in developing my research objective, I also felt that it was important to remain open to exploring the nurses' *experience*; I therefore felt reluctant to remove this word in favour of focusing solely on coping processes. I was aware that exploring experience in order to understand how individuals make sense of specific phenomena is one of the central tenets of IPA

(Smith, 2007). However, I felt that my own study was seeking to explore participants' experiences and establish *how* they were using these to engage in a particular social process (i.e. managing and coping).

Reflections about this decision were made as a result of several discussions with my research team. These helped me to consider more fully the subjective nature of the term 'experience', especially in relation to how it is used in qualitative research. I could not help questioning how the fundamental experience of existing within a certain context could not be intrinsic to the social processes under scrutiny. I realised that in parallel with personal construct theory (Kelly, 1955), my own understanding of 'experience' is that it is acted upon by individuals in order to test their understandings of their own constructed realities. Therefore I felt my role as researcher was to establish both the construction of experience and how this was being used by community nurses working in COPD in order for them to manage and cope in their roles. Consideration of this particular issue also helped to affirm my own social constructivist epistemological position, thus enabling me to pay attention as to how my constructions could influence the emerging theory.

In light of this, I was aware of the importance of ensuring that I was using an appropriate approach within GT and that this fitted with my own epistemological position. Charmaz' (2006) constructivist approach appeared to meet the requirements of my research, particularly in its emphasis on the influence of the researcher's own social constructions in the development of theory. However in defence of classic GT, Glaser (2002) argued the level of passivity involved in GT interviewing (i.e. the researcher predominantly listens as opposed to asking

questions) ensures very little opportunity for mutually constructed interpretations of the data to be made. Initially I found myself caught up in this debate, and felt associated anxiety about who was 'right'. However, further consideration of these issues allowed me to realise that such debate was illustrative of the extent to which GT methods themselves are open to great subjectivity. Understanding this enabled me to recognise that in the world of qualitative research there are no definitive right or wrong answers. As a consequence of this learning, I was able to focus on producing a piece of research that I hoped would generate interest, whilst maintaining an openness to answering and/or debating questions about a topic that had not been explored before.

3.4 Conclusion

I have found undertaking this research challenging, thought provoking and interesting. Exploring the experiences of community nurses working with patients who have COPD has increased my understanding of the challenges these nurses face in relation to an illness that is fraught with uncertainty. The utilisation of a constructivist GT methodology required me to understand my own perspectives of emerging categories and consider these in relation to the generation of the resulting model. This was particularly relevant in considering my own relationship with death. The experiences I have encountered whilst undertaking this research have inspired me with a greater interest to work clinically with issues of an existential nature and to conduct further research with those who are affected by COPD.

3.5 References

- Bush, T. (2005) Overcoming the barriers to effective clinical supervision. *Nursing Times*, 101, 38–41.
- Charmaz, K, (2006). *Constructing Grounded Theory: A practical guide through qualitative analysis*. Sage Publications
- Cresswell, J. W. (2008) *Educational Research: Planning, conducting and evaluating quantitative and qualitative research*. Upper Saddle River. New Jersey: Pearson
- Fleming, I., & Steen, L. (2012). *Supervision and Clinical Psychology: Theory, Practice and Perspectives*. (2nd Ed.) New York & London: Routledge.
- Glaser, B. G. (2002). Constructivist Grounded Theory? *Forum: Qualitative Social Research*, 3 (3).
- Hovarth, A. O. (2001). The Alliance. *Psychotherapy*, 38 (4).
- Kelly, G. A. (1955). *The Psychology of Personal Constructs, volume 1 a theory of personality*. London: Routledge.
- Smith, J. A. (2007). Hermeneutics, human sciences and health: Linking theory and practice. *International Journal Of Qualitative Studies On Health And Well-Being*, 2, 3-11.
- Yalom, I. D. (2008). *Staring at the Sun: Overcoming the Dread of Death*. Great Britain: Piatkus.

Appendix A: Author Guidelines for Journal of Aging & Mental Health and Journal of Qualitative Health Research



Aging & Mental Health

Published By: Routledge

Volume Number: 15

Frequency: 12 issues per year

Print ISSN: 1360-7863

Online ISSN: 1364-6915

Instructions for Authors

SCHOLARONE MANUSCRIPTS™

This journal uses ScholarOne Manuscripts (previously Manuscript Central) to peer review manuscript submissions. Please read the [guide for ScholarOne authors](#) before making a submission. Complete guidelines for preparing and submitting your manuscript to this journal are provided below.

Aging & Mental Health has a new editorial e-mail address: amh@ucl.ac.uk. General enquiries can be sent to m.orrell@ucl.ac.uk.

Use these instructions if you are preparing a manuscript to submit to *Aging & Mental Health*. To explore our journals portfolio, visit <http://www.tandfonline.com>, and for more author resources, visit our [Author Services](#) website.

Aging & Mental Health is an international peer-reviewed journal publishing high-quality, original research. All submitted manuscripts are subject to initial appraisal by the Editor and if found suitable for further consideration, to peer-review by independent anonymous expert referees. All peer review is double blind and submission is online via [ScholarOne Manuscripts](#). We encourage the submission of timely review articles that summarize emerging trends in an area of mental health or aging, or which address issues which have been overlooked in the field. Reviews should be conceptual and address theory and methodology as appropriate.

Aging & Mental Health considers all manuscripts on the strict condition that

- the manuscript is your own original work, and does not duplicate any other previously published work, including your own previously published work.
- the manuscript is not currently under consideration or peer review or accepted for publication or in press or published elsewhere.
- the manuscript contains nothing that is abusive, defamatory, libellous, obscene, fraudulent, or illegal.

Please note that *Aging & Mental Health* uses [CrossCheck™](#) software to screen manuscripts for unoriginal material. By submitting your manuscript to *Aging & Mental Health* you are agreeing to any

necessary originality checks your manuscript may have to undergo during the peer-review and production processes.

Any author who fails to adhere to the above conditions will be charged with costs which *Aging & Mental Health* incurs for their manuscript at the discretion of *Aging & Mental Health's* Editors and Taylor & Francis, and their manuscript will be rejected.

Manuscript preparation

1. General guidelines

[↑Back to top.](#)

- Manuscripts are accepted only in English. Any consistent spelling and punctuation styles may be used. Please use single quotation marks, except where 'a quotation is "within" a quotation'. Long quotations of 40 words or more should be indented without quotation marks.
- Manuscripts may be in the form of (i) regular articles not usually exceeding **5,000 words** (under special circumstances, the Editors will consider articles up to 10,000 words), or (ii) short reports not exceeding **2,000 words**. These word limits **exclude** references and tables. Manuscripts that greatly exceed this will be critically reviewed with respect to length. Authors should include a word count with their manuscript.
- Manuscripts should be compiled in the following order: title page (including Acknowledgments as well as Funding and grant-awarding bodies); abstract; keywords; main text; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figure caption(s) (as a list).
Please supply all details required by any funding and grant-awarding bodies as an Acknowledgement on the title page of the manuscript, in a separate Funding paragraph, as follows:
For single agency grants:
This work was supported by the <Funding Agency> under Grant <number xxxx>.
For multiple agency grants:
This work was supported by the <Funding Agency #1> under Grant <number xxxx>; <Funding Agency #2> under Grant <number xxxx>; and <Funding Agency #3> under Grant <number xxxx>.
- Structured [Abstracts](#) of not more than 250 words are required for all manuscripts submitted. The abstract should be arranged as follows: Title of manuscript; name of journal; abstract text containing the following headings: Objectives, Method, Results, and Conclusion.
- Each manuscript should have 3 to 5 [keywords](#).
- Search engine optimization (SEO) is a means of making your article more visible to anyone who might be looking for it. Please consult our guidance [here](#).
- Section headings should be concise. The text should normally be divided into sections with the headings Introduction, Methods, Results, and Discussion. Long articles may need subheadings within some sections to clarify their content.

- All authors of a manuscript should include their full names, affiliations, postal addresses, telephone numbers and email addresses on the cover page of the manuscript. One author should be identified as the corresponding author. Please give the affiliation where the research was conducted. If any of the named co-authors moves affiliation during the peer review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after the manuscript is accepted. Please note that the email address of the corresponding author will normally be displayed in the article PDF (depending on the journal style) and the online article.
- All persons who have a reasonable claim to authorship must be named in the manuscript as co-authors; the corresponding author must be authorized by all co-authors to act as an agent on their behalf in all matters pertaining to publication of the manuscript, and the order of names should be agreed by all authors.
- Biographical notes on contributors are not required for this journal.
- Authors must also incorporate a [Disclosure Statement](#) which will acknowledge any financial interest or benefit they have arising from the direct applications of their research.
- For all manuscripts non-discriminatory language is mandatory. Sexist or racist terms must not be used.
- Authors must adhere to [SI units](#). Units are not italicised.
- When using a word which is or is asserted to be a proprietary term or trade mark, authors must use the symbol ® or TM.
- Authors must not embed equations or image files within their manuscript.

Manuscript Submission Guidelines: *Qualitative Health Research* (QHR)

Qualitative Health Research (QHR) is an international, interdisciplinary, refereed journal for the enhancement of health care and furthering the development and understanding of qualitative research methods in health care settings. We welcome manuscripts in the following areas: the description and analysis of the illness experience, health and health-seeking behaviors, the experiences of caregivers, the sociocultural organization of health care, health care policy, and related topics. We also consider critical reviews; articles addressing qualitative methods; and commentaries on conceptual, theoretical, methodological, and ethical issues pertaining to qualitative inquiry.

QHR is a member of the [Committee on Publication Ethics](#).

This Journal recommends that authors follow the [Uniform Requirements for Manuscripts Submitted to Biomedical Journals](#) formulated by the International Committee of Medical Journal Editors (ICMJE)

Please read the guidelines below then visit the Journal's submission site to upload your manuscript. Please note that manuscripts not conforming to these guidelines may be returned.

Only manuscripts of sufficient quality that meet the aims and scope of QHR will be reviewed.

As part of the submission process you will be required to warrant that you are submitting your original work, that you have the rights in the work, that you are submitting the work for first publication in the Journal and that it is not being considered for publication elsewhere and has not already been published elsewhere, and that you have obtained and can supply all necessary permissions for the reproduction of any copyright works not owned by you.

1. Article types

2. Editorial policies
 - 2.1 Peer review policy
 - 2.2 Authorship
 - 2.3 Acknowledgements
 - 2.4 Funding
 - 2.5 Declaration of conflicting interests
 - 2.6 Research ethics and patient consent
 - 2.7 Clinical trials
 - 2.8 Reporting guidelines
 - 2.9 Data
3. Publishing Policies
 - 3.1 Publication ethics
 - 3.2 Contributor's publishing agreement
 - 3.3 Open access and author archiving
 - 3.4 Permissions
4. Preparing your manuscript
 - 4.1 Word processing formats
 - 4.2 Artwork, figures and other graphics
 - 4.3 Supplementary material
 - 4.4 Journal layout
 - 4.5 Reference style
 - 4.6 English language editing services
5. Submitting your manuscript
 - 5.1 How to submit your manuscript
 - 5.2 Title, keywords and abstracts
 - 5.3 Corresponding author contact details
6. On acceptance and publication
 - 6.1 SAGE Production
 - 6.2 Access to your published article
 - 6.3 Online First publication
7. Further information

1. Article types

Each issue of QHR provides readers with a wealth of information - book reviews, commentaries on conceptual, theoretical, methodological and ethical issues pertaining to qualitative inquiry as well as articles covering research, theory and methods in the following areas:

Description and analysis of the illness experience
 Experiences of caregivers
 Health and health-seeking behaviors
 Health care policy
 Sociocultural organization of health care

A Variety of Perspectives

QHR addresses qualitative research from variety of perspectives including: cross-cultural health, family medicine, health psychology, health social work, medical anthropology, medical sociology, nursing, pediatric health, physical education, public health, and rehabilitation.

In-Depth Timely Coverage

Articles in QHR provide an array of timely topics such as: experiencing illness, giving care, institutionalization, substance abuse, food, feeding and nutrition, living with disabilities, milestones and maturation, monitoring health, and children's perspectives on health and illness.

Authors are responsible for obtaining permission from copyright holders for reproducing any illustrations, tables, figures or lengthy quotations previously published elsewhere. For further information including guidance on fair dealing for criticism and review, please visit our [Frequently Asked Questions](#) on the [SAGE Journal Author Gateway](#)

4. Preparing your manuscript

4.1 Word processing formats

Preferred formats for the text and tables of your manuscript are Word DOC, RTF, XLS. LaTeX files are also accepted. The text should be double-spaced throughout and with a minimum of 3cm for left and right hand margins and 5cm at head and foot. Text should be standard 10 or 12 point. Word and LaTeX templates are available on the [Manuscript Submission Guidelines](#) page of our Author Gateway.

4.2 Artwork, figures and other graphics

For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's [Manuscript Submission Guidelines](#). Please refer to clause 4.5 for information on SAGE Language Services.

Figures supplied in color will appear in color online regardless of whether or not these illustrations are reproduced in colour in the printed version. For specifically requested color reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

4.3 Supplementary material

This journal is able to host additional materials online (e.g. datasets, podcasts, videos, images etc) alongside the full-text of the article. These will be subjected to peer-review alongside the article. For more information please refer to our guidelines on submitting supplementary files, which can be found within our [Manuscript Submission Guidelines](#) page.

4.4 Journal layout

In general, QHR adheres to the guidelines contained in the Publication Manual of the American Psychological Association ["APA"], 6th edition (ISBN 10:1-4338-0561-8, softcover; ISBN 10:1-4338-0559-6, hardcover; 10:1-4338-0562, spiral bound), with regard to manuscript preparation and formatting. These guidelines are referred to as the APA Publication Manual, or just APA. Additional help may be found online at <http://www.apa.org/>, or search the Internet for "APA format."

4.5 Reference style

QHR adheres to the APA reference style. [Click here](#) to review the guidelines on APA to ensure your manuscript conforms to this reference style.

4.6 English language editing services

Authors seeking assistance with English language editing, translation, or figure and manuscript formatting to fit the journal's specifications should consider using SAGE Language Services. Visit [SAGE Language Services](#) on our Journal Author Gateway for further information.

5. Submitting your manuscript

5.1 How to submit your manuscript

QHR is hosted on SAGE Track, a web based online submission and peer review system powered by ScholarOne™ Manuscripts. Visit <http://mc.manuscriptcentral.com/qhr> to login and submit your article online.

Appendix B: Quality Checklist (Tooth et al., 2004)

<22 low >22<44 med >44 high	Carr, et al, 2000,	Carr et al, 2001	Schulz et al, 2001	Bonanno, Wortman et al, 2002	Carr, 2004 - black & white	Carr, 2004 Desire to Remarry	Boener, Wortman & Bonanno 2005	Prokos, Reid Keene, 2005	Burton, Haley, Small, 2006	Brown et al, 2008	Reid Keene, Prokos, 2008	Taylor, Kuchibhati a, Ostbye, Plassman, Clipp, 2008	Coleman & Neimeyer, 2010	Pai,Carr, 2010	Hwa, Ingersoll-Dayton, 2011	Galatzer-Levy & Bonanno 2012	Carr, Sharp, 2013
1 Are the objectives or hypotheses of the study stated?	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2
2 Is the target population defined?	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2
3 Is the sampling frame defined?	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2
4 Is the study population defined?	2	2	2	2	2	2	2	2	2	2	2	2	1	2	2	2	2
5 Are the study setting (venues) and/or geographic location stated?	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2
6 Are the dates between which the study was conducted stated or implicit?	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2
7 Are eligibility criteria stated?	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2
8 Are issues of "selection in" to the study mentioned?	2	2	2	2	2	2	2	2	2	2	2	0	2	2	2	2	2
9 Is the number of participants justified?	2	2	2	2	2	2	2	1	1	2	2	2	2	2	2	2	1
10 Are numbers meeting and not meeting the eligibility criteria stated?	1	1	0	1	2	1	1	2	1	1	1	1	0	2	1	1	1
11 For those not eligible, are the reasons why stated?	1	1	2	1	1	0	1	2	2	2	1	1	2	1	2	1	1
12 Are the numbers of people who did/did not consent to participate stated?	1	1	0	1	1	0	0	0	0	1	0	0	1	1	1	0	1
13 Are the reasons that people refused to consent stated?	0	2	0	0	2	2	1	1	0	0	0	0	2	2	2	0	2
14 Were consenters compared with nonconsenters?	0	2	0	0	2	2	0	0	0	0	0	0	2	0	0	1	2
15 Was the number of participants at the beginning of the study stated?	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2
16 Were methods of data collection stated?	2	2	2	2	2	2	2	2	2	2	2	1	1	2	2	2	2
17 Was the reliability (repeatability) of measurement methods mentioned?	2	1	1	2	2	2	2	1	1	1	1	1	1	1	1	1	1
18 Was the validity (against a "gold standard") of measurement methods mentioned?	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
19 Were any confounders mentioned?	2	2	2	2	2	1	2	2	2	2	2	2	2	2	2	2	2
20 Was the number of participants at each stage/wave specified?	2	2	0	2	2	2	2	2	0	2	1	0	2	2	2	2	0
21 Were reasons for loss to follow-up quantified?	2	2	0	0	2	2	2	1	0	0	0	2	1	2	2	2	2
22 Was the missingness of data items at each wave mentioned?	0	0	0	0	0	0	0	0	0	0	0	1	0	0	0	2	0
23 Was the type of analyses conducted stated?	2	2	2	2	2	2	2	2	0	2	2	2	2	2	2	2	2
24 Were "longitudinal" analysis methods stated?	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2
25 Were absolute effect sizes reported?	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2
26 Were relative effect sizes reported?	0	0	0	0	0	0	0	0	2	0	0	0	0	0	0	0	0
27 Was loss to follow-up taken into account in the analysis?	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2
28 Were confounders accounted for in analyses?	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
29 Were missing data accounted for in the analyses?	0	0	0	0	0	0	0	0	0	0	0	2	0	0	0	2	0
30 Was the impact of biases assessed qualitatively?	2	2	2	2	2	2	2	1	2	2	2	2	1	2	2	2	2
31 Was the impact of biases estimated quantitatively?	2	2	2	2	2	2	2	2	0	2	2	2	2	2	2	2	2
32 Did authors relate results back to a target population?	2	2	2	2	2	2	2	2	0	2	2	2	2	2	2	2	2
33 Was there any other discussion of generalizability?	2	2	2	2	2	2	2	0	2	2	2	2	1	2	2	2	2
Total scores out of 66	50	53	44	48	55	51	49	46	41	48	45	45	50	51	52	51	53
	high	high	med	high	high	high	high	high	med	high	high	high	high	high	high	high	high

Appendix C: Brief Summaries of the Longitudinal Studies

Changing Lives of Older Couples Study (CLOC)

The CLOC study is a large multi-wave prospective study of spousal bereavement, conducted in the USA (Detroit and the Michigan Standardised Metropolitan Statistical Area SMSA) between 1987 and 1992. 1532 married men and women took part in the study. Eligibility criteria required that participants were English speaking, members of a married couple where the husband was at least 65 years old.

Baseline (face-to-face) interviews were conducted between 1987 and 1988, spousal loss was subsequently monitored during a five year period. 316 respondents were contacted for possible interview (from a total of 335 respondents known to have lost a spouse during the five year period); 263 respondents participated in at least one of the three follow-up interviews conducted at 6, 18 and 48 months post-loss.

Control participants from the baseline sample were matched with each widowed person, according to age, sex and race. All control participants were re-interviewed at 6, 18 and 48 months. There were fewer control participants at 6 months (Wave 1), due to funding being cut and not reinstated until later.

The CLOC data includes over 3000 variables designed to measure social, psychological and physical functioning in older adults.

Health Retirement Study (HRS)

The HRS is a longitudinal study based in the USA. It aims to explore the changes in the workforces and the health transitions that adults older than 50 years undergo as they reach retirement, and in the years that follow. Launched in 1992, the HRS

surveys a representative sample of Americans every two years, collecting information about disability, physical health and cognitive functioning in addition to work, pensions and financial data.

In Taylor et al. (2008), a total number of 1967 spousal couples were recruited from the HRS. Eligibility required each spouse to have responded to the 1993 interview, and for at least one member of the spouse to have reported one or more instrumental or basic activity of daily living limitations on one or more surveys. All participants included in this sample were 70 or older. Moves to nursing homes and deaths were checked following the initial baseline interviews.

The Cardiovascular Health Study (CHS) and Caregiver Health Effects Study (CHES)

The CHS was an observational study of risk factors for cardiovascular disease in adults aged 65 years and older, carried out between 1989 and 1999. The CHES is an ancillary study of the CHS, which was initiated in 1993 in 4 US communities. With a sample of approximately 400 spousal caregivers and 400 matched controls, it measured quality of life and physical and psychological health outcomes. Caregivers were defined as individuals whose spouse had difficulty with at least one activity of daily living (ADL) or instrumental activity of daily living (IADL). Non-caregivers were individuals whose spouse had no difficulty with ADL or IADLs. Participants were interviewed annually for three years, and a fourth wave of data was collected two years after the third wave.

The study carried out by Schulz et al. (2001) included individuals who reported being widowed at wave 2, 3, or 4.

Sources and References:

Nesse, R. M., Wortman, C. B., & House, J.S. (2015) *CLOC Changing Lives of Older Couples*, Retrieved 28 April 2015 from <http://cloc.isr.umich.edu/overview.htm>

Schulz, R., Beach, S. R., Lind, B., Martire, L. M., Zdaniuk, B., Hirsch, C.,...Burton, L. (2001). Involvement in Caregiving And Adjustment to Death of a Spouse. *JAMA*, 285 (24).

Taylor, D. H., Kuchibhatla, M., Ostbye, T., Plassman, B. L, & Clipp, E. C. (2008) The effect of spousal caregiving and bereavement on depressive symptoms. *Aging and Mental Health*, 12(1), 100- 107

University of Michigan. (2015). *Health and Retirement Study. A longitudinal study of Health, Retirement and Aging*. Retrieved on 28 April 2015, from <http://hrsonline.isr.umich.edu/>

Appendix D: Interview Schedule

Beginning of interview:

“Thank you for agreeing to meet with me to talk about your experiences of working with patients who have been diagnosed with Chronic Obstructive Pulmonary Disease (COPD). I expect this interview to last between 30 minutes and one hour; however, if you wish to stop the interview at any point, please let me know. As mentioned in the information provided previously, the interview will be recorded in order for me to obtain an accurate record of what is said. The recording of your interview and subsequent transcription will be anonymous and therefore not identifiable to you. I will only breach confidentiality if I become worried that the safety of you or another person might be at risk. Please remember that you have the right to withdraw from this study at any time.”

“Do you have any questions or concerns about the research study?”

Request “consent to participate form” to be signed

Provide “basic demographics questionnaire” to also be completed

Possible questions and prompts to use during interview

This list is not exhaustive; questions will be used only as a prompt and will be altered according to simultaneous and continuous analysis of the data

Overall Experience:

Can you tell me about your experience of working with patients who have COPD?

How did you feel when you first encountered a patient with COPD?

Possible prompts to help elicit information about experience and coping:

- Working in patients’ homes
- Now compared with the past
- End of life care

New diagnosis versus longstanding illness

Coping:

How do you think working with patients who have COPD has affected you personally?

Which aspects of the illness do you find more of a challenge to cope with?

Which aspects of the illness do you find more rewarding to work with?

How do you feel when patients talk to you about the aspects of the illness that you find more difficult?

What do you think makes you respond in the way that you do?

What do you think has changed about you as a result of working with patients who have COPD?

Tell me about any strengths that you have discovered about yourself through working with this patient group?

What is important to you when working with this patient group?

Possible prompts to help elicit coping processes:

- Particularly difficult/challenging situations
- Physical aspects of illness i.e. Breathlessness, Oxygen
- Emotional aspects of illness i.e. Patient anxiety
- End of life/terminal diagnosis/death and dying
- Advice complied with versus advice ignored
- Support structures
- Self-care

De-briefing prompts:

- Thank the participant for taking part
- Ask them if they have any questions or concerns that they would like to discuss
- Provide participants with an information sheet containing details about who to contact if they wish to complain, and who to contact should they require any further support
- Ask participant if they would like a copy of their transcript
- Ask participant how they would like to be sent a summary of the findings of the research, i.e. post or email

Appendix E: Participant Information Sheet

Coventry University
Priory Street, Coventry CV1 5FB
Telephone 024 7688 8328
Fax 024 7688 8702

Programme Director
Doctorate Course in Clinical Psychology
Dr Eve Knight
BSc Clin.Psy.D. CPsychol

THE UNIVERSITY OF
WARWICK



Coventry and Warwickshire 
Partnership Trust

Participant Information Sheet

Research study title

“Community Nurses’ Experiences of Providing Palliative Care to Patients Diagnosed with COPD”

Invitation

I would like to invite you to take part in a research study. Please take the time to read the following information about the study prior to deciding to take part. Please do not hesitate to contact me should you have any questions or concerns about the study. This is a research study and has no direct link with your role as a nurse working for the Coventry and Warwickshire Partnership Trust.

What is the purpose of this study?

The study aims to gain a greater understanding of the experiences of community/district nurses working with patients who have been diagnosed with Chronic Obstructive Pulmonary Disease (COPD). I would like to learn about how you have learned to cope with working with patients who have this disease.

Who can take part?

I am inviting any community/district nurse who meets the following criteria to take part in this study:

- To have worked autonomously (without supervision) as a nurse for at least one year post-graduate/qualification.
- To have experience of working in the community with patients with a diagnosis of COPD at any stage of the illness)
- To be English speaking

Page 1

Dean of Faculty of Health and Life Sciences

Dr Linda Merriman Mphil PhD DpodM CertEd Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805

Head of Department of Psychology

Professor James Tresilian BSc PhD University of Warwick Coventry CV4 7AL Tel 024 7657 3009

Do you have to take part?

There is absolutely no obligation for you to take part in this study; choosing not to take part will not affect your current (or future) role in the team. If you decide that you would like to take part, you will be asked to sign a consent form. Signing the consent form does not mean that you cannot change your mind about taking part. You are free to withdraw from the study at any time within four weeks from the date of your interview (by contacting Annabel Goodall on 024 7688 8328), without giving a reason.

What happens if you choose to take part?

You will need to complete, sign and return the “consent to be approached” form supplied with this pack. You can also contact me or any of the research team by email. Once contacted, I will approach you by telephone (unless otherwise specified) to arrange to meet with you for an interview. I will arrange for the interview to take place within your working hours and at a location convenient to you.

When we meet for the interview I will request that you read through and sign a “consent to participate” form. You will be given plenty of opportunity before signing the form to ask any questions you might have about the study. Once the “consent to participate form” is signed I will ask you to complete the “basic demographic questionnaire” which asks you to provide some factual information about yourself, this will help to give a context for your role within nursing. Following this and you are ready, we will commence the interview. During the interview I will ask you questions relating to the experiences you have had working with patients diagnosed with COPD. I expect the interview to last between 30 minutes and an hour. A digital recording of the interview will be taken so that I have an accurate record of what is said. You can ask to stop the interview at any time.

The interview will be typed up word for word and this transcript and the original recording will be kept in a locked cabinet or on a password protected computer. Both will be treated confidentially; your name will not be attached to the recording or the notes. In all of the reports and documentation for the research project we will refer to you by a false name. Whilst your words may be quoted in the write up of the research, your name and identifying details will be removed.

As a way of ensuring that what is said during the interviews is being interpreted accurately I will also ask you if you would be happy to provide feedback on the results of the study as it develops.

What are the possible disadvantages and risks of taking part?

It is possible that talking about your experience of working with patients who have COPD might evoke some upsetting or distressing feelings for you. The interview can be stopped at any time if it becomes difficult for you to continue. Once the interview has finished, you will be able to ask questions and/or raise concerns with the researcher. You will also be given information on who to contact in the event that the interview causes any work-related or emotionally difficult feelings

What are the possible benefits of taking part?

We already know that working with patients who have COPD provide a different set of challenges to working with those who have other illnesses, it is hoped that the information obtained from this study will improve our understanding of the roles of nurses in this field. In turn this may have a positive impact on patient care, service outcomes and how nurses can be best supported in their roles in addition to informing other research in this area.

Will taking part in this study be confidential?

All information collected about you will be kept strictly confidential. Confidentiality will only be breached in exceptional circumstances, i.e. if there are concerns about your safety or the safety of others; in which case, the researcher has a duty to follow the relevant safeguarding procedures and protocol.

What will happen to the results of this study?

The results of this study will be used by the primary researcher, Annabel Goodall, as part of the academic requirement of the Coventry and Warwick Doctoral Course in Clinical Psychology. The results of this study will be put forward for publication in psychology or nursing journals. Feedback at a service level will be provided through the Coventry and Warwickshire Partnership Trust's clinical governance and research and audit meetings. A copy of the results will be provided to all participants.

What will happen to the information you provide?

The information you provide during the interview will be transcribed into written form, after which the recording will be erased. The written transcript will be stored in a secure room at Coventry University for a period of five years, after which it will be destroyed.

Who is organising and funding the research?

The study is being organised by Annabel Goodall at the Coventry and Warwick Doctoral Course in Clinical Psychology. No payment is being received by any of the organisers for conducting this study.

Who has reviewed this study?

This study has been reviewed by the Coventry University Research Ethics Committee, and the Coventry and Warwick Partnership Trust's Research and Development team.

Contacts for further information

I hope you find this information helpful; if you have any further questions about the research study, please don't hesitate to contact the primary researcher, Annabel Goodall on 02476888328. Alternatively you may contact the other members of the research team, Dr Laura Hayward and/or Dr Jane Everett on 02476707962.

Thank you for taking time to read this information.

Appendix F: Demographics Questionnaire

Coventry University
 Priory Street, Coventry CV1 5FB
 Telephone 024 7688 8328
 Fax 024 7688 8702

Programme Director
Doctorate Course in Clinical Psychology
 Dr Eve Knight
 BSc Clin.Psy.D. CPsychol

THE UNIVERSITY OF
WARWICK



Coventry and Warwickshire **NHS**
 Partnership Trust

Basic Demographics Questionnaire

1. What is your gender?
2. What is your current age?
3. What is your ethnicity? Please tick the appropriate box in the table below

White	British	
	Irish	
	Other White	
Mixed	White and Black Caribbean	
	White and Black African	
	White and Asian	
	Other Mixed	
Asian or Asian British	Indian	
	Pakistani	
	Bangladeshi	
	Other Asian	
Black or Black British	Caribbean	
	African	
	Other Black	
Chinese or other ethnic group	Chinese	
	Other ethnic group (please specify)	

4. Please state the number of hours per week you work as a nurse for the trust?
5. How long have you been employed as a nurse (post-graduation/qualification)?
6. Approximately how many patients have you cared for who have a diagnosis of COPD?

Dean of Faculty of Health and Life Sciences

Dr Linda Merriman Mphil PhD DpodM CertEd Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805

Head of Department of Psychology

Professor James Tresilian BSc PhD University of Warwick Coventry CV4 7AL Tel 024 7657 3009

Appendix G: Ethics Approval Letters

Community nurses' experiences of providing palliative care to patients diagnosed with COPD

P22/0

REGISTRY RESEARCH UNIT ETHICS REVIEW FEEDBACK FORM

(Review feedback should be completed within 10 working days)

Name of applicant: Annabel Goodall.....

Faculty/School/Department: [Faculty of Health and Life Sciences] Clinical Psychology

Research project title: Community nurses' experiences of providing palliative care to patients diagnosed with COPD

Comments by the reviewer

1. Evaluation of the ethics of the proposal:

Every reasonable effort seems to have been made to address the ethical issues raised by this research

2. Evaluation of the participant information sheet and consent form:

None

3. Recommendation:

(Please indicate as appropriate and advise on any conditions. If there are any conditions, the applicant will be required to resubmit his/her application and this will be sent to the same reviewer).

☒

Approved - no conditions attached

☐

Approved with minor conditions (no need to re-submit)

☐

Conditional upon the following – please use additional sheets if necessary (please re-submit application)

☐

Rejected for the following reason(s) – please use other side if necessary

☐

Not required

Name of reviewer: Anonymous.....

Date: 30/04/2014

Annabel Goodall

Page 1 of 1

27 April 2015

National Institute for Health Research Clinical Research Network: West Midlands
Fourth Floor, Rotunda (ADA40014)
University Hospitals Coventry & Warwickshire NHS Trust
University Hospital
Clifford Bridge Road
Coventry
CV2 2DX

6th August 2014

Mrs Annabel Goodall
Trainee Clinical Psychologist
Coventry University
Dept of Clinical Psychology
James Starley Building
Coventry
CV2 2DX

Dear Mrs Goodall

Project Title: Community Nurses experiences of providing care to patients with COPD
R&D Ref: PAR220514

I am pleased to inform you that the R&D review of the above project is complete, and NHS permission has been granted for the study at Coventry and Warwickshire Partnership NHS Trust. The details of your study have now been entered onto the Trust's database.

The permission has been granted on the basis described in the application form, protocol and supporting documentation. The documents reviewed were:

Document	Version	Date
Research Proposal	1.0	31.05.2014
Basic Demographic Questionnaire	2.0	31.05.2014
Consent Form to be approached	3.0	21.06.2014
Participant Information Sheet	3.0	21.06.2014
Post Interview Information Sheet	2.0	31.05.2014
Poster	2.0	31.05.2014
Consent to Participate Form	4.0	06.08.2014
R and D Form	149955/617683/14/548	23.05.2014
SSi Form	149955/617684/6/956/237240/300956	27.05.2014

All research must be managed in accordance with the requirements of the Department of Health's Research Governance Framework (RGF), to ICH-GCP standards (if applicable) and to NHS Trust policies and procedures. Permission is only granted for the activities agreed by the relevant authorities.

Please note: The interview audio recordings you will collect for this study can be transcribed at your home and immediately transferred to an appropriate Trust or University server providing that there is full anonymity of the data. Furthermore, all study documentation that includes participant identifiable data must be stored at Coventry University in a locked filing cabinet.

All amendments (including changes to the local research team and status of the project) need to be submitted to the REC and the R&D office in accordance with the guidance in IRAS. Any urgent safety measures required to protect research participants against immediate harm can be implemented immediately. You should notify the R&D Office within the same time frame as any other regulatory bodies.

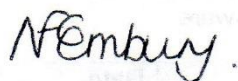
It is your responsibility to keep the R&D Office and Sponsor informed of all Serious Adverse Events. All SAEs must be reported within the timeframes detailed within ICH-GCP statutory instruments and EU directives.

In order to ensure that research is carried out to the highest governance standards, the Trust employs the services of an external monitoring organisation to provide assurance. Your study may be randomly selected for audit at any time, and you must co-operate with the auditors. Action may be taken to suspend Trust approval if the research is not run in accordance with RGF or ICH-GCP standards, or following recommendations from the auditors.

You will be sent an annual progress report which must be completed in order to ensure that the information we hold on our database remains up to date, in line with RGF requirements.

I wish you well with your project. Please do not hesitate to contact me should you need any guidance or assistance.

Yours sincerely



Natassia Embury
RM&G Facilitator

Cc: Veronica Ford, Community Health Services, CWPT
Laura Hayward, Academic Supervisor, Coventry University
Jane Everett, Academic Supervisor, Coventry University
Dr Caroline Gordon, Academic Supervisor, Coventry University

Research, Development and Innovation Department

Head of R,D&I: Ceri Jones - Tel: 024 7696 6198

R,D&I Operations Manager: Tammy Holmes - Tel: 024 7696 6196

Research Portfolio Development Manager: Deborah Griggs - Tel: 024 7696 4958

Research Associate, Governance: Isabella Petrie - Tel: 024 7696 6069

R,D&I Research Coordinator: Hannah Williamson - Tel: 024 7696 4995

R,D&I Research Coordinator: Kim Holmes - Tel: 024 7696 6202

R,D&I Senior Administration Officer: Sonia Kandola - Tel: 024 76 96 6195

R,D&I Administration Specialist: Stephanie Jones - Tel: 024 7696 6197

Date: 30 May 2014

Annabel Goodall

Dear Annabel,

Letter of access for research

This letter confirms your right of access to conduct research through University Hospitals Coventry and Warwickshire NHS Trust for the purpose and on the terms and conditions set out below. This right of access commences on **2nd June 2014** and ends on **1st June 2017** unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project.

The information supplied about your role in research at University Hospitals Coventry and Warwickshire NHS Trust has been reviewed and you do not require an honorary research contract with this NHS organisation. We are satisfied that such pre-engagement checks as we consider necessary have been carried out.

You are considered to be a legal visitor to University Hospitals Coventry and Warwickshire NHS Trust premises. You are not entitled to any form of payment or access to other benefits provided by this NHS organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

While undertaking research through University Hospitals Coventry and Warwickshire NHS Trust, you will remain accountable to your employer, The University of Warwick, but you are required to follow the reasonable instructions of **Ceri Jones, Head of Research, Development & Innovation** in this NHS organisation or those given on her behalf in relation to the terms of this right of access.



We **Care.** We **Achieve.** We **Innovate.**

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with University Hospitals Coventry and Warwickshire NHS Trust policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with University Hospitals Coventry and Warwickshire NHS Trust in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on University Hospitals Coventry and Warwickshire NHS Trust premises. You must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of any other contract holder and you must act appropriately, responsibly and professionally at all times.

If you have a physical or mental health condition or disability which may affect your research role and which might require special adjustments to your role, if you have not already done so, you must notify your employer and the Trust (Sonia.Kandola@uhcw.nhs.uk) prior to commencing your research role at the Trust.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (<http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf>) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that this NHS organisation accepts no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence.



We **Care.** We **Achieve.** We **Innovate.**

University Hospitals Coventry and Warwickshire



NHS Trust

You must not undertake regulated activity if you are barred from such work. If you are barred from working with adults or children this letter of access is immediately terminated. Your employer will immediately withdraw you from undertaking this or any other regulated activity and you **MUST** stop undertaking any regulated activity immediately.

Your academic supervisor is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

University Hospitals Coventry and Warwickshire NHS Trust will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

If your current role or involvement in research changes, or any of the information provided changes, you must inform your employer through their normal procedures. You must also inform your nominated manager in this NHS organisation.

Yours sincerely

Isabella Petrie
Research Associate Governance



We **Care**. We **Achieve**. We **Innovate**.

Appendix H: Consent to Participate Form

Coventry University
Priory Street, Coventry CV1 5FB
Telephone 024 7688 8328
Fax 024 7688 8702

Programme Director
Doctorate Course in Clinical Psychology
Dr Eve Knight
BSc Clin.Psy.D. CPsychol

THE UNIVERSITY OF
WARWICK



Coventry and Warwickshire **NHS**
Partnership Trust

Consent to Participate Form

Title of the study: Community nurses' experiences of providing palliative care to patients diagnosed with COPD

Before consenting to participate in this study, please ensure that you have read and fully understood the participant information sheet. Please contact me should you have any questions or concerns about the study.

Name of principal researcher: Annabel Goodall, Trainee Clinical Psychologist, Universities of Coventry and Warwick

- I confirm that I have read and understood the participant information sheet ☐
- I understand that I may withdraw from the study at any time within four weeks of my interview without any requirement for explanation or justification of reasons ☐
- I understand that my role at will not be affected by my decision to withdraw from the study ☐
- I understand that my interview will be audio recorded, transcribed word for word and that excerpts of my interview may be included in the future write ups of the study ☐
- I understand that all interview transcripts, my name and any other identifiable information will be anonymised for the purposes of confidentiality ☐
- I understand that confidentiality will only be breached in exceptional circumstances i.e. when concerns are raised about my own safety or the safety of others ☐
- I give permission for the researcher's supervisors at Coventry University and the Coventry Community Health Team (CWPT) to have access to my interview transcripts ☐
- I am happy to be asked for feedback on the developing study, prior to it being completed ☐
- I would like a copy of the study once it is complete ☐

Dean of Faculty of Health and Life Sciences
06/08/2014 Version 4
Professor Annabel Goodall, Coventry University, Priory Street, Coventry CV1 5FB, Tel 024 7679 5805
Head of Department of Psychology
Professor James Tresilian BSc PhD, University of Warwick, Coventry CV4 7AL, Tel 024 7657 3009

www.coventry.ac.uk

I agree to take part in the above study

Signed

Date

Signed by researcher

Date

Appendix I: Post-Interview Information Sheet

Coventry University
Priory Street, Coventry CV1 5FB
Telephone 024 7688 8328
Fax 024 7688 8702

Programme Director
Doctorate Course in Clinical Psychology
Dr Eve Knight
BSc Clin.Psy.D. CPsychol

THE UNIVERSITY OF
WARWICK



Coventry and Warwickshire **NHS**
Partnership Trust

Post-Interview Information Sheet (CWPT)

Thank you for taking part in this research study, which is based on exploring the experiences of community nurses working with patients who have a diagnosis of COPD. It is hoped that you will have found the interview process an enjoyable experience; however, we understand that it may have evoked some difficult feelings for you.

In the event of work/role related issues being evoked as a result of this study, please contact your line manager, or alternatively a HR representative from the Coventry and Warwickshire Partnership Trust.

If the study evokes emotionally distressing feelings that you would like additional support to manage, you may make a self-referral to the CWPT Employee Improving Access to Psychological Services team by calling 07920581981, or alternatively contact your GP.

If you have any complaints about the researcher, or any part of this research process, please contact the Clinical Psychology Department at Coventry University, contact details as follows:

Clinical Psychology Doctorate
Faculty of Health and Life Sciences
Coventry University
James Starley Building
Priory Street
Coventry
CV1 5FB
Tel: 024 7688 8328

Should you have any questions or concerns about the study, please contact the primary researcher, Annabel Goodall either by writing to the above address or calling 024 7688 8328.

31/05/2014 Version 2

Dean of Faculty of Health and Life Sciences

Dr Linda Merriman Mphil PhD DpodM CertEd Coventry University Priory Street Coventry CV1 5FB Tel 024 7679 5805

Head of Department of Psychology

Professor James Tresilian BSc PhD University of Warwick Coventry CV4 7AL Tel 024 7657 3009

Appendix J: Excerpt from Transcript

Focused Codes

Making self available to patients

144 you know I'm only a phone call away. Cos we had the COPD team and it used to be the

145 [redacted] Team and if they were acutely unwell we'd go out but it didn't continue and it only

Holistic approach

146 focused on the disease, whereas we focus on the whole, you know so actually we follow patients

Seeing patients right through to death

147 through right to death. Which is nice for patients, it's nice for me as well you know, to care for

Giving patients a good death

148 somebody to the end and if I give them a nice death, you know and they've died where they want to

Importance of environment

149 die and I've supported the family then I get job satisfaction after that. I never go to funerals cos

Never go to funerals

150 that's my way of coping, it's bizarre isn't it? You know over the years with patients, but it is very sad

151 A: Hmm so you don't go to funerals?

Past vs present

152 P7: No, don't go to funerals. You know I used to years ago but, over the years because I've been a

Confronting vs avoiding closure

153 nurse for 20 years now and I've been out in the community for 18 of those years and I've seen a lot

Seeing a lot of death

154 of death, and actually I feel sad for the family, you know, cos it's who's left. Because lots of people

Reality of COPD

155 who are dying are suffering, you know, like your cancer patients or your COPD patients and you

156 know, or heart failure, you know and they're sitting in the chair and gasping for breath and they

Dying is a release

157 have no quality of life, you know and actually when they do go, it's a release. Lots of my patients will

Patients expressing a desire to die

158 say "I've had enough now", and I say to them "I'm sorry the Lord above doesn't want you yet", you

159 know I had a lady who's, she'd got COPD, she'd had Christmas and she phoned me on Friday, got

160 swollen legs cos you find that patients over 75 aren't quite as concordant either, you know,

161 complaining of swollen legs but she hadn't taken her diuretics for three days, but she said "I'd like to

Confronting the subject of death

162 go into [redacted]. Cos I'd done her DNAR, cos I'm quite comfortable talking about DNARs over the

Experience increases confidence

163 years, I know junior members of staff aren't, but I like to do it when they're well, rather than

Being attuned to when talking about death is right

164 frighten them you know, when they're unwell and you say "do you want to talk about resuscitation"

165 and they think that you're actually trying to tell them something in a round-about way. But she said

166 "I want to go to [redacted]", "why do you want to do that" "I've had enough". When actually clinically,

167 she was stable bar her swollen legs and I said to her, "I'm really sorry but I don't think you'll be going

Confronting difficult subject of death

168 to heaven but I'll see if there's a bed available" and I actually got her in because of her mood.

Line by Line Codes

Nurse making herself

available for patients "lifeline"

Focusing on the whole patient

Following patients through to death

Caring for patients until

the very end Satisfying job - giving good death

Never going to funerals

Way of coping

Previously went to funerals

Feeling sad for families

Lots of people are suffering

Gasping for breath

Dying can be a release

Lots of patients want to die

Telling patients it isn't time

Older patients less agreeable

to treatment

Patient not taking medication

Nurse feels comfortable talking

about DNARs

Less experienced nurses "juniors"

less comfortable

Choosing right time

to talk

Awareness of how patient may

interpret conversation

Listening to patient expressing

choice

Helping patient to get to a

hospice

- 169 A: So what's that like, working with somebody, a patient who actually wants to die and is saying that
- 170 to you and you're having, you're kind of having to tell them that it's not happening, what's that like
- 171 for you with them?
- 172 P6: All my patients when I first go in, I say to them about our relationship, that I need to be open and *the importance of open & honest rels* *Telling patients that there's a need for openness*
- 173 honest and I'm always open and honest, even you know like non-compliant patients, I will say to *managing difficult patients* *COPD & co-morbidities*
- 174 them, I had this gentleman who was COPD but he got diabetes and he kept having hypos but he *Empowering patients to self-manage* *Giving patients responsibility*
- 175 wasn't eating you know and I will say to him "you have some responsibility as well as I have, what is *over themselves*
- 176 the point of me keep coming in here and keep telling you, you know, what you need to do and you *Telling patient what he needs to do*
- 177 don't do it you know and you're going into hospital because you're not doing, if you don't eat and *Empowering patients to take responsibility* *Easier to be honest/direct now*
- 178 you give yourself insulin you're going to have a hypo you know" I don't find it difficult now, years ago *Experience increases confidence/understanding*
- 179 I did, I think that's experience isn't it? I think when I start my, when I first go in, I sort of slip in the *Defining role* *Needing to let patients know her role*
- 180 DNR and the erm, because I say "part of my role is I, we look at planning for the future and you know *Confronting death* *Explaining resuscitation*
- 181 erm whether you'd like to be resuscitated and can I just explain what that it is" cos lots of people *choices*
- 182 think that if they sign that they're not going to have any treatment so I go there, and and if I get any *Being attuned to patient's readiness* *Watching out for patient cues*
- 183 cues from them that they'd like to do that, but if not I leave if, but then later, if they start to *Preparing patient for death* *Sitting patient down to talk*
- 184 deteriorate I sit them down and say you know "your conditions starting to deteriorate now and we *importance of being open & honest* *Being open & honest is necessary when the time has come*
- 185 need to plan". So I find being open and honest with my patients and I think, a lot of patients, if they *Importance of patient choice* *Listening to patients' choice*
- 186 say "I don't want to discuss, you know, I want to be resuscitated" that's fine and I can have *Accepting when limit is met* *Patient choice is most important*
- 187 professionals saying "they need a DNR" but if the patient chooses not to, they choose not to you *Feeling that providing good care*
- 188 know. And I think, I think where I cope with the sadness and things is if I can provide good care and *Desire to do/give best care* *protects nurse*
- 189 they have the best quality. I always say my goals are when I come in to see them, my goals are, *Empower self-management* *Setting goals to help patients be as independent as possible*
- 190 although we are admission avoidant, is to make them as well as they can be and as independent as *Importance of environment* *Helping patients to stay where they want to*
- 191 possible you know and ensure that they stay where they want to stay you know, so if they're in their *little home then that's it. So it is about well and and it's about, people do get very depressed -*
- 192 *COPD patients are always grieving* *COPD patients can get very depressed*
- 193 patients with COPD, they get very depressed and um, they go actually they're always grieving. *Reality of disease progression* *COPD patients always grieving*
- 194 Because every time they have, because with COPD what you have is, you have lung function

Appendix K: Example of Memo:

Significance of environment: This seems relevant as a category (although perhaps not main?). The participants construct it in the following ways:

- As a 'tool' for informing them about their patient's health status
- As a (known) variable that **patients are able to exert choice over in relation to where they die**. This is then linked to external **pressures felt or ignored around the reduction of hospital admissions**. This is linked to the participants' overall acceptance that 1) some hospital admissions are unavoidable 2) some patients choose to go to hospital, which conflicts with the popular idea of home being the best place to die 3) sometimes patients do die where they don't want to. The significance of environment therefore **links strongly to Good versus Bad death**. This also relates to the constructs of good and bad places to die – nurses conceive hospitals, ambulances as being bad/negative as opposed to hospice or home. I think Significance of Environment also plays a part in **the need for professionals (and patients and families) for clarity over their EOL choices. There is also something here about different boundaries to work with, which seems helpful??**
- Nurses construct the care provided in the home environment as different to hospital – it allows them a greater ability to “nurse the individual” (taking a **holistic approach**), in addition to being a facilitator/hindering factor to the development of relationships with the patients and families.
- There is a different power dynamic when nursing is taking place in the home – “we are a guest in their homes”, “I feel privileged to be allowed in”

Appendix L: Table of Codes

Conceptual Category 1: Working with Time	
Axial Codes	Focused Codes
<i>Negotiating with time</i>	Missed opportunities: people die Making the most of today Not a 9-5 job Quality/duration of relationships
<i>Integrating experience</i>	Experience reduces fear Perception of lack of experience as a barrier Experience increases confidence Using experience to show understanding and empathy Using experience to inform/educate others
Conceptual Category 2: Death: Travelling to The Precipice	
Axial Codes	Focused Codes
<i>Accompanying others on their journey to death</i>	Preparing patients/relatives for death Confronting the difficult/sensitive subject of death Talking about death : obstructions and facilitative factors Patients wanting to die Opportunities and obstructions to closure
<i>Managing their own sense of mortality</i>	Acceptance of death being a part of the role Constructing a personal death narrative
Conceptual Category 3: Managing the Reality of COPD	
Axial Code	Focused Codes
<i>An unpredictable and life limiting illness</i>	The reality of disease progression Moving beyond a treatment focus The need for clarity over EOL choices
<i>Observing the struggle</i>	COPD is frightening Watching patients struggle Patients wanting to die
Conceptual Category 4: Trusting Relationships	
Axial Code	Focused Code
<i>Attuning self to the needs of others</i>	Duration and quality of relationship is important Endearing personalities Identifying with patients Taking a direct/honest/truthful approach Accepting patient choices (not to comply)

	<p>Being attuned to relative's readiness to confront reality of COPD</p> <p>Taking a mediating role (hospital and patient and family and patient)</p> <p>Patient focus – holistic approach</p> <p>Conflicting with needs of family, then shifting focus to family (on patient's death)</p> <p>Needing to reassure</p> <p>Taking a mediating role (hospital and patient and family and patient)</p> <p>Awareness of family's emotional pain</p> <p>Using relatives to facilitate care</p> <p>Death representing shift from patient to family focus</p> <p>Awareness of relatives' needs as distinct from patient</p>
<i>Intuition versus external reassurance</i>	<p>Feeling appreciated – external validation</p> <p>Trusting intuition</p>
<i>Perceiving relationships as mutually beneficial</i>	<p>Positive personalities</p> <p>Forming close/special relationships</p>
<i>Drawing on external support</i>	<p>Drawing on experience of others</p> <p>The importance of team support</p> <p>Crucial support of other professionals</p>
Conceptual Category 5: Giving	
Axial Codes	Focused Codes
<i>An implicit desire to give</i>	<p>Trusted/trusting relationships</p> <p>A desire to give/do their best (seeking self-validation)</p> <p>Balancing hope with reality</p> <p>Containing the emotions of others</p> <p>Negotiating between the need to reassure versus the consequence of over-dependence</p> <p>Wanting to breathe for the patient</p>
<i>A perceived ability to give</i>	<p>Giving a good death versus consequence of a bad death</p> <p>Empowering patients to self-manage vs preparing them to expect barriers</p> <p>Informing/educating patients and families</p> <p>Improving quality of life</p> <p>Using experience to demonstrate empathy and/or understanding</p>
Conceptual Category 6: Evaluating Own Resilience	
Axial Codes	Focused Codes

<i>Assessing personal cost</i>	Emotional containment versus emotional involvement
<i>Protecting self</i>	<p>Confronting versus avoiding death/closure</p> <p>Ending relationships with the living as well as the dead</p> <p>The use of reflection – when to be and when to do (action versus reflection)</p> <p>Seeking external validation as a way of protecting the self (needing to be appreciated)</p> <p>Protecting personal relationships</p> <p>Protecting limited capacity for compassion</p> <p>“Me time” is important</p> <p>Physical exercise as a form of therapy</p> <p>Talking helps</p> <p>Using support of personal relationships (staying connected)</p> <p>Balancing respect between patient/relative choice/behaviour and maintaining professional integrity</p>
Conceptual Category 7: Negotiating the Limits	
Axial Codes	Focused Codes
<i>Managing personal limitations</i>	<p>Accepting of personal limitations</p> <p>Accepting/coping when the limit has been met</p> <p>Being human</p> <p>Defining the role (to patients and professionals)</p> <p>Allowing other professionals to take over</p>
<i>Limitations of personal autonomy</i>	<p>Smoking: damage done versus belief in the benefits of quitting</p> <p>Managing patients who ask for help but won't help themselves</p> <p>Choosing when to stop resisting the uncompliant patient</p> <p>Reassurance versus over-dependent patients</p> <p>Barriers to forming trusting relationships</p>
<i>Limitations of the environment</i>	<p>Pressures to prevent/reduce hospital admissions</p> <p>The significance of the patient's environment</p>